

National Disability Forum

Wednesday, April 19, 2023

>> Hello, everyone, and welcome to Social Security's National Disability Forum on Focusing on Aspects of Childhood Disability and Childhood SSI, Part 1. I would now like to turn it over to Steve Rollins, Associate Commissioner for Disability Policy at Social Security Administration.

>> Good afternoon, and good morning to those on the West Coast. Thank you for joining us today. As James said, my name is Steve Rollins, and I am the Associate Commissioner for the Office of Disability Policy here at the Social Security Administration. I have the pleasure of welcoming you to our 23rd National Disability Forum entitled Focusing on Aspects of Childhood Disability and Childhood SSI. On behalf of Acting Commissioner Kijakazi, SSA executives, and everyone at the Social Security Administration, we hope all of you are well. Before I continue, I would like to go over some housekeeping items. First, I want to inform everyone that the National Disability Forum is a public forum and may include representatives of the press so any statements or comments made during the forum may be considered on the record. This virtual forum is being recorded and will be available on the National Disability Forum's website within four weeks after today's forum. And second, we have disabled the chat, the microphone, and video feature for our attendees. If you dialed in to this teams meeting, please use your phone's mute feature. Third, we are offering two accessibility features today. We have an American Sign Language interpreter and closed captioning. If you would like closed captions, please go to your

MS Teams toolbar, select the three dots entitled "more," select language and speech option, and then select "Turn on live captions."

Okay. So, now it is my honor to welcome and introduce the Acting Commissioner of the Social Security Administration, Dr. Kilolo Kijakazi. Before becoming Acting Commissioner, Dr. Kijakazi served as the Deputy Commissioner for Retirement and Disability Policy. Prior to joining the Social Security Administration Dr. Kijakazi served as an institute fellow at the Urban Institute where she developed collaborative partnerships to expand and strengthen the Urban's rigorous research agenda to effectively communicate findings to diverse audience and recruit and retain a diverse resource staff at all levels. Dr. Kijakazi has also conducted research in the areas of economic and retirement security, social insurance policy, structural racism, and the racial wealth gap. She holds a Ph.D. in Public Policy from George Washington University and a Master's in Social Work from Howard University. Dr. Kijakazi's enthusiastic dedication to Social Security and commitment to the public that we serve is unparalleled. I and so many others here are thankful for her leadership. So, Acting Commissioner, it's my sincere honor to welcome you to the National Disability Forum. And the floor is all yours. Thank you.

>> Thank you, Steven, for your warm welcome. And it is my pleasure to join you for our 23rd National Disability Forum. These forums are an important platform for exchanging ideas and gathering input. We will use the information learned today and, in the future, future forums, as we evaluate our policies. Social Security is a critical lifeline for people with disabilities. Consider the numbers: In fiscal year 2022, SSA paid over \$200 billion dollars in disability benefits to over

14 million people. According to the latest Census Bureau Data, over 1 million children would have been living in poverty in 2021 if the family had not received Social Security benefits. In addition, over 1 million children with a qualifying disability received SSI payments in 2021. This fiscal year, our most critical priority is to address the backlog of initial disability claims. The pandemic, combined with high attrition, created backlogs. Initial disability claims pending have now reached over 1 million. We are hiring staff at SSA and in the State Disability Determination Services, or DDSs, because that is fundamental to improving service. I also assembled a Disability Tiger Team to develop and implement additional solutions. The team has established a cadre of adjudicators and reviewers to assist with initial claims and reconsiderations for states with some of the greatest backlogs. The team has also established a cadre of attorneys from the Office of Hearings Operations who are conducting disability hearings in the DDSs to free up experienced state disability examiners to work on initial claims. They have also established a cadre of SSA retirees who have agreed to come back to provide assistance where needed at any point in the disability process. We are using advanced tools to help review medical files that are often voluminous. To facilitate more efficient collection of medical evidence, we are establishing a national contract with medical and psychological consultants, and we issue guidance permitting tele-help for certain consultive examinations. To drive effective solutions, the team has employed analytics to identify bottlenecks in the disability determination process and factors contributing to them. Additionally, my executive team and I are visiting with state DDS's and learning firsthand about the issues they are facing and working with them on proposed solutions. Improving service will take time and sufficient resources. We appreciate the increase in funding we received from Congress for FY 2023. This will help us maintain our

current level of service and hire needed employees. But the funding level was 55% of President Biden's budget request and not sufficient to make the necessary improvements we had hoped to make this year. To begin to improve service we will need President Biden's full \$15.5 billion dollar budget request for FY 2024. While having enough trained employees is necessary to improve service, it will take time for the new hires to become fully productive as experienced -- as experienced employees help mentor and train them. We anticipate that some performance measures will show improvement in FY 2023, while others will show temporary degradation as we process more of the cases that have been pending the longest, average processing times temporarily increase before evening out. For example, when our offices were closed for in-person hearings due to the pandemic we could not conduct hearings for people who did not want to have a hearing by telephone or video. As we process these oldest cases average processing times will increase. Once we have completed these cases the average processing time will decline again. We know that backlogs make their way through the appellate process, so it is imperative that we stay on top of reducing the hearings backlog, too. Our hearings backlog reached its lowest level in 20 years in FY 2022 and by FY 2024, we expect to eliminate the backlog and prevent its reoccurrence. With sufficient funding we expect to see other improvements in 2024. This will occur once our new hires are fully trained and become productive and the people who are training them resume their casework full time. However, these outcomes will be budget driven. The SSI application is long and complex because of the legislative requirements for the program. To address this problem, we have taken several steps to ensure that SSI is accessible. In March 2022, we implemented an online protective filing tool for SSI. This tool allows an individual or their representative to provide a minimal amount of

information to preserve that date as the date of their filing for SSI. Parents of minor children and third parties such as family members, representatives, or members of advocacy groups can also use the tool to help someone request an appointment. After the online process is complete, an SSA employee will follow-up with the applicant for a full interview. Since the tool was launched, we have received about 600,000 submissions. To successfully inform the public, we are counting on you to help us share accurate information with communities across the country to raise awareness about eligibility or benefits including for children and to help people avoid scams. The information shared in the forum today will help all of us understand potential trends and impacts. The forum will also assist us in identifying other ways SSA might address potential barriers to accessing SSI, as well as develop non-medical evidence and specific medical evaluation issues prevalent with children. Thank you to all the panelists for your work and all that you do. I appreciate everyone who is taking time out of your day to add your perspective to this important topic. Your questions and insights make a difference. So, I will turn it back to you, Steve.

>> Okay. Thank you, Acting Commissioner. We do truly appreciate you taking the time to join us here today. Okay. So, as previously mentioned, there is no chat feature available today for you to make comments. If, however, you do wish to ask a question of our panelists or provide a comment, you can do so via email at NationalDisabilityForum, which is all one word, @SSA.gov. Again, that is the NationalDisabilityForum@ssa.gov. Please include your name in any email question that you submit. Now, when submitting a question, please do not include any personally identifiable information such as a Social Security Number or an address. We are

monitoring the in-box throughout the forum, and we will share questions with the moderator as time allows. If your questions are not answered during the forum, we certainly will make every effort to answer your question via email after the forum or share them with the appropriate office. In a few weeks we will post a link to the recording of this forum on our National Disability Forum website at www.ssa.gov/NDF. And then from there you look in the outreach section under today's tab for 192023. Okay, now, in terms of the purpose of the forum, as with all national disability forums, today gives you, our stakeholders, an opportunity to share your unique insights directly with us, including us, the policymakers, here within the agency. The NDF is not intended to be a means to reach an agreement on any issue and, you know, Social Security's participation is strictly for the purpose of gaining insight by listening to the panelists and the responses to your questions or comments. By sharing your thoughts and experiences you will help us shape the future of Social Security by strengthening our disability policy development and contributing to our continued effort to address equity within our disability policy and practices. I hope you are just as excited as we are to hear from the expert panel about focusing on aspects of childhood disability and childhood SSI. As a reminder, this is part 1 of a two-part series. Part two will be held Wednesday, May 17th. So, the purpose of this forum is to learn from our panelists and you, how Social Security can improve aspects of childhood SSI and childhood disability. During today's forum, we will focus on three major topics. First, overcoming potential barriers to SSI. The second is developing non-medical evidence. And then the third is specific medical evaluation issues. Dr. James Perrin will moderate today's panel discussion. After the panel discussion, there will be an open questions and answer session for you to be able to submit a question for the panelists. Introducing Dr.

Perrin, Dr. Perrin is 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 has also served as Past President of the Ambulatory Pediatric Association and directed the Autism Intervention Research Network on Physical Health for seven years. Dr. Perrin was Founding Editor of Academic Pediatrics. He has 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 our SSA executives, please visit the National Disability website, click on National and Disability Forums from the right-side menu, then select the 4/19/2023 tab. We would like to extend our sincere appreciation to Dr. Perrin and all the panelists for their participation in today's discussion. Dr. Perrin, we welcome you and the floor is yours. Thanks.

>> Thank you, Steve, for this warm welcome. And I very much join SSA in welcoming our panelists and the attendees to this National Disability Forum Focusing on Aspects of Childhood Disability and Childhood SSI Part 1. Today we will have initially a closed discussion with five panelists, experts in their field. After the discussion we will take questions via email. And as time permits, I will share your questions with the panelists. As Steve said, if you want to ask a question or provide a comment, please include your name and location and your email question, and send it to the NationalDisabilityForum, all one word, @ssa.gov. The chat line will not be open during the discussion segments. All questions must be received by email. Before

we begin this afternoon's discussion, I would like to take a few moments to recognize how critical the SSI program is to U.S. children and youth with major disabilities in their families. The Acting Commissioner commented on the fact that a million children in the United States were preserved from living in poverty as a result of SSI in 2021. For many families, SSI provides the difference between homelessness, hunger, and poverty, and allows them instead the opportunity to focus together on best ways to support the growth and development of the child receiving SSI. We also know from several sources and studies that there are many children and families who could benefit from SSI but who currently do not. And the deliberations today may help us understand how to improve what we're doing.

>> Let's begin the transition to today's discussion on focusing on aspects of childhood disability and childhood SSI. I am going to initially introduce the panel and then ask each of them in turn to introduce themselves and what their work is and to share some of the comments they would like to sort of set the frame for this afternoon. And then we'll go back and have a series of questions that were shared with us prior to today for each of the members of the group. Let me start with David Whittenburg of Mathematica. Then we will go to Amy Harfeld with the Children's Advocacy Institute. Michael Laveer with Haverford College. Mallory Finn Legg with the Kennedy Krieger Institute, and then with MaryAnn Strawhacker with the Heartland Area Education Agency. Again, bios of these people are all available on the National Disability Forum website. Let me start with David.

>> Thanks, James. Hello, everybody, I'm Dave Whittenburg and I am a parent and a researcher with 25 years of experience in studying SSI and I am passionate about improving youth outcomes which is why I am here today. As a researcher I seek to bring clarity to programs for better decision-making. And as I was thinking about today's talk, I was inspired by Margaret Gould Stewart's Ted Talk so I structured my opening remarks around what she said about designing forms and taking an audacious and a humble approach to form development and really thinking about how these forms, how we can develop these forms to apply evidence to operations which I think is a crucial tool to building in both accessibility and efficiencies into the process. And so, what does the research state? SSI is a crucial tool in combating poverty as noted by Dr. Kijakazi and Perrin. However, it is vital that we thoughtfully examine how administrative processes affect the intake and long-term results to those who rely on the program. Research and anecdotal evidence reveal that the SSI program does pose distinct challenges especially regarding local contacts, administrative processes, and form complexities. So, what lessons can we borrow from other places? My idea is to refine the forms used to apply for SSI with input from applicants and administrators, drawing from industries that prioritize access and experience. Sounds fairly basic, but despite the challenges, there are big needs for this information particularly given the diversity of SSI applicants and the need for consistent scoring among administrators. So, it's essential to test with very diverse populations. This approach requires both the audacity to design scalable forms and the humility to acknowledge the need for iterations because we are likely not to get it right. So, why do I suggest this approach and how does this frame some of the questions we'll be talking about today? And the context I'm going to use is if you want an acronym is LAF, local context, administrative

processes, and forum complexities. And whenever talking about SSI, I like to start with local context fact matter a lot in SSI. There are large variations in SSI participation, particularly at the county level when you look at different MAPS. And local factors impact program access and information gathering. Some areas have resources like Legal Aid to help with applications, while others lack these resources. So, tailoring outreach and addressing these factors can enhance program participation and access. Point two, administrative processes can significantly impact access to SSI and eventually ultimate outcomes. For instance, staffing levels and fundings for, say, continuing disability reviews can influence program durations and caseloads and one of the things that is probably not as well-known is the large hike in community disabilities in recent years which has substantially changed program durations on SSI. And the third point that I want to make is going to form complexity is a significant challenge in SSI. Their lengthy multiple-page forms can pose challenges for applicants and administrators. I would almost encourage everybody to go through this process on the phone. It is hard. SSA's need to collect information from various sources like schools and medical providers directly impacts decision making and that places the first point about local context matters because schools and medical providers vary quite a bit not only by county but within counties. So, what are some of the ideas to improving form design and what do I mean by the audacity to task, test, and humility to modify and evolve the equitable. So, first in applying to SSI to tackle these issues we require the audacity to test forms for accessibility as in other industries while humbly gathering feedback from diverse SSI applicant groups. But understanding the burden of form completion and striving for user friendliness we can acknowledge the unpredictability of this process but move towards an evidence-based approach that enhances the program effectiveness across regions.

And what's really new here about the idea that I am posing is that this type of testing isn't just a few focus groups. It's really going in-depth across the country and doing a lot more in-depth testing to understand how people experience these forms, who do they get it from. Note that I know this might not be as easy as SSA has to file some very complicated federal regulations in administering the programs, but more can be done in moving these forums on what I call a compliance-based culture to an accommodating culture. So, in closing, designing forms for all users across disability status, race, ethnicity, and location for populations SSA serve and equally important in a way that administrators can consistently make disability determinations is critical to creating products and services that work for everybody. This takes both audacity to test and scale and humility to recognize this change. Thanks.

>> Thank you, David. Amy?

>> Good afternoon, everyone. My name is Amy Harfeld. I serve as the National Policy Director for the Children's Advocacy Institute which is a non-profit based at the University of San Diego School of Law. I have been an attorney in the child welfare arena for over 20 years as well as an advocate. I have prosecuted child abuse and neglect cases, represented children in their cases, represented parents in their cases, and served as a federal policy advocate for many years now. I am here today because I want to draw awareness to a little-known pocket of SSI recipients, young people in foster care. About 10% of the 400,000 children in foster care in the U.S. receive SSA benefits. Most of those are disability benefits. Some of them are survivor benefits. And many more than that may be eligible. What happens when kids are in care is that agencies

routinely screen them and apply for benefits for all youth who come into care. And when benefits are awarded, the agency automatically appoints itself to serve as the representative payee which is not allowed. When checks start coming in for the disabled foster youth, those checks are automatically pocketed by the foster care agency for the cost of the child's care which is already their obligation to pay for under federal and state law. When children are receiving benefits and care, the vast majority of them never know somebody has applied for their benefits. Are never aware that any benefits have been approved or received. And neither they nor their attorney have a chance to have input about who serves as the rep payee or how the money might be used in the child's best interest. As a young person who I used to represent used to say if I had, if I had known foster care was a service, I was paying for I might have asked for my money back. So, I wanted to draw some attention to this. SSA has addressed this frequently in its literature and rules, in fact, says quite clearly that SSA states that cases involving foster care are among the most sensitive that SSA encounters and that it is critical that SSA do everything possible to protect the rights of children who for that time are not able to rely on their parents to do so. The exciting thing is that there is a lot of change underway to draw awareness to the fact that disabled children in foster care have no opportunity to participate or have a say in the use of their benefits and currently have their benefits used in a way that goes against what SSA says. When money is used to pay for the cost of their care and the agency was already supposed to pay for their care and is paying for foster care for all the other kids except disabled youth, that money is not being used for the use and the benefit for the child and is not being used in their best interest. There are lots of states who are trying to change this right now. And SSA has indicated that new rules are coming out to better protect

foster children and make sure that their benefits are being used in a way that benefits them. There are new rules that we look forward to make sure that kids are notified when somebody applies for their benefits when they are over the age of 15. And, of course, their attorneys and guardian's ad litem must also know that benefits have been applied for. We need to make it clear that when agencies are supplanting their own obligations to pay for care, that's not a proper use of disability benefits. We need to make sure that we're enforcing the good rules and laws that are on the books already by SSA internally. And we need to encourage the agency to play a much more active role in enforcing its rules about rep payees, on foster care agencies who are not always abiding by their fiduciary obligations to act in the children's best interest when they are serving. So again, I thank you for this opportunity and will pass it along.

>> Thank you, Amy. And raising the issues of foster care, very helpful. Michael?

>> Yes, thank you for having me. I'm really excited to be part of this panel today. My name is Mike Levere. I am an economist and I primarily study people with disabilities through the lens of labor and health economics, and I'm particularly interested in children of disabilities. And so, sort of think of, I come at this as a researcher, who you know is interested in policy-oriented topics and kind of some of my research relates to first trying to understand what are some of the supports and services that we can offer youth to help improve outcomes. And so, I'll talk today shortly about ABLE accounts, which are really important accounts that can promote financial security for youth with disabilities, And young adults as well. And then I'm doing some research right now looking at how the minimum wage affects employment, among people with

disabilities. I think somewhat more related to the topics of today's panel discussion, is really trying to understand the factors that lead people to participate in disability benefits. And so you know I'll talk more as the session goes on I am sure about the way that schools can be a really important channel through which families can learn about benefits, and as well as I have done research on like health insurance and the role that, you know, the fact that when people qualify for SSI, they almost always also get Medicaid, can be a motivating factor to lead people to participate in the program. And I think this later portion is really important, because as we see some of the trends that participation in SSI has decreased since 2014, and applications have been declining for a little bit longer than that, ensuring that we are able to reach all of the people who are eligible for SSI benefits involves really thinking about what are the things that are driving people to participate in the first place, and what are the ways in which they are learning about benefits? And so we can leverage a more comprehensive understanding of those channels to think about how we can conduct outreach, how we can ensure that we can access and inform people and help them to participate when they are eligible, and in particular the ways that some of this, you know, may be related to systemic barriers that people of color may, and low income people may face in accessing these programs. So, I'm real excited to be part of the panel today and thank you so much for having me. And I'll turn it back to you.

>> Thanks, Mike. It will, you know, help us a lot with strategies to increase enrollment. Mallory?

>> Hi, my name is Mallory Legg, and I'm an attorney. I'm the Director of Project HEAL, which stands for Health, Education, Advocacy, and Law which is a medical legal partnership at

Kennedy Krieger Institute in Baltimore, Maryland. We provide legal services to Kennedy Krieger patients primarily in special education matters. So, SSI is really not a legal practice area for me, but I do in representing low-income families, work with a lot of families who are experiencing difficulties navigating the SSI application and appeals process. And so, while you know I don't necessarily represent families through this process, I do have a lot of interaction with families, particularly the low-income families who may, you know may need help through this process. So, what I did was I received, I reached out to parents and guardians, whom I've formerly represented and currently represent and then also reached out to school systems staff who I work with throughout the, throughout the special education process and ask for their feedback in ways that they think that we can improve the SSI process. And so, throughout the questions that I'm answering today, I'm going to share some of their feedback. And I thought it might be helpful getting it from you know the ground level. And so, the primary feedback from the school staff was really related to unsurprisingly the volume of paperwork and the amount of coordination that is required to get through that paperwork, to coordinate the multiple staff, and then to really do the paper and pencil list of submitting that paperwork. And so one of the primary pieces of feedback from school systems staff was having increased technology capabilities throughout that process, To be able to have everyone at the school be able to log into one portal system, upload documents directly to that portal, and be able to work on these applications simultaneously, rather than passing it back and forth amongst staff people, paper and pencil copy, and then have to mail or fax it in. So that was the primary feedback from school staff. I'll share more detail about that when we get to that part of the discussion. And then for families I received a variety of feedback, and that really depends on the families'

demographics and preferences, so I will share that as well. So, I appreciate you including me on this panel, and I look forward to it.

>> Mallory, thanks. You can help to put SSI in an interesting context and talk about strategies again for improving. MaryAnn? MaryAnn, are you still on mute, I think?

>> I sure am. I'm sorry.

>> Thank you.

>> I am MaryAnn Strawhacker, Personal Education Nurse Consultant. I work at Heartland Area Education Agency. We cover 53 public schools, 29 private schools in the central part of the state. I also am representing the National Association of School Nurses. I've been a director there, have contacts all over the United States, have done a lot of work with children with disabilities. My entire career really has been focused on that. The first part of my career, I worked in the Children's Hospital in neonatal intensive care, PICU. A lot of our graduates from neonatal intensive care would end up in the special education system. After having done that, and worked inpatient, then the last 30 years I have worked as a special education nurse. My job is to interpret how a child's disability impacts their education, and how do we adjust their IEP, their Individual Education Program, to meet those needs through program modifications, through instructions, specially designed instruction, through all the different tools and services necessary to do that. I can tell you I, I echo comments of the other presenters in that the

paperwork, cumbersome is an understatement. Many, many parents struggle to fill out that paperwork. I have sat down at a kitchen table with a number of parents and tried to help them work their ways through it and I struggled. And I understand all of the medical terminology. When it comes to schools, I, there again, the teacher gets this, and I went back and just really looked at the most recent form. I hadn't done it for a couple of years but looked at the most recent form. It asked for teachers to give medical information, which is really inappropriate, and I'm sure it is a turn-off to them and challenging for them. My, my biggest takeaway from this and I ran it by our parent coordinator, our agency employs everything from psychologists, educational consultants, I'm the nurse consultant, we have audiologists and audio metrists, OTs, PTs, we have all of those services, because in rural, Iowa, it is not practical to have that for every district. So, when I talked with our parent educator, who is a parent that has a child with a disability, that was what we had a great discussion on. I think there needs to be a different way to structure those, those applications. I think that the parents obviously have to do their own financial information, we can't do that for them. I believe that the medical community should provide the medical information. It is really challenging for some of our families, they hear the terms, they know some of the terms, but they can't explain it like a medical professional can. And then the final part would be to have the educators focus on that IEP. And I have a lot of things I will talk about later for other questions, but that is enough for me for today. Thank you for asking.

>> Thanks very much, MaryAnn. And again, a good perspective to help us going forward. So, we obviously have an incredibly skillful experienced panel for this good discussion today. Why

don't we move right into some of the questions that we have received in the past to talk them through. Could you tell us, Mallory, perhaps I'll start with you, what are some of the preferred modes of communication, email, text, phone, snail mail that SSI applicants prefer? And do you have a sense that these preferences might vary based on demographics?

>> So absolutely. I think it varies a lot based on demographics, but I think also based on age of the person applying. So, you know, I have clients, I work with you know some clients, many of my clients who are low income may not use email as much. They may, but they may be very likely to respond to a text message, and this could be because they are not sitting in front of a computer all day for work. But, you know, they see the text message coming across their notifications on their phone pretty much immediately. So, in talking to my clients and my former clients, I received pretty much any form of communication as an answer under the sun. So, there was no necessary, there was not necessarily one single form of communication. But one, a grandparent I worked with, did have a good piece of input I thought, that basically said why doesn't SSA ask what kind of communication we prefer. And so, you know, asking if a family prefers email, prefers phone, prefers in-person and trying, you know, knowing that it is not always feasible to do everything via a single source of communication, and trying to make that the primary mode of communication for a family is -- you know, I have families who move a fair amount and may not necessarily update their mailing address on a regular basis. And so, some of that paper mail gets lost in the shuffle. So, I would say that that's my primary thought, is that there is not necessarily one mode of communication I would say is best but trying to

work with families when possible and when feasible to see what is best for that particular family.

>> Thanks. Dave, do you have any comments on this or thoughts?

>> Yeah, James. You know I think also some of the things we have to consider when thinking about the mode of communication is what is in the content of that communication, and so to just give a few examples here. Text communications, and I should reiterate, I fully support what Mallory said, we should ask people which communications they prefer, that is the number one takeaway. But like when we are thinking about content, there is certain content that might lend itself more to say a text communication. For example, for SSA to send quick reminders or updates especially sort of simple questions of say reminders of earnings updates. Phone communications are, when you have more nuance communications, so when, or urgent matters to resolve complex issues, an overpayment is coming or there is detailed explanations where you need to dig into, you know, what are the sources of, of unearned income or earned income that might be affecting a person's benefits because they truly provide a lifeline. Email communications, these can be good for non-urgent inquiries, digital document submission, when a written communication is necessary. And finally mailed communications are probably most important when you have to have an official documentation or an accommodation for somebody that might not be able to interact with those other modes.

>> Thanks. So different, so I think you're both suggesting, first of all, we should know what the applicants prefer as a start. And that there may be different strategies and logics for using different kinds of communication. So, so what kinds of technology, updates, or technological outreach mechanisms could help with simplifying the application process? I mean, for example, having a Chat Now feature to the SSA website, an SSA app that assists, that users could use in the application process, or an app that connects a variety of players, the users, SSA, state agencies, other resources as well. Mike, do you have any thoughts on this?

>> Sure. So, I think more than necessarily any specifics, is I think all of the ideas that you just mentioned are good. I want to highlight generally giving, you know, making it easier for people to engage, and I think all of those sorts of apps can make it easier and simpler for people to engage and get the information they need is what is really important. You know, there has been a lot of research done, that trying to minimize what is known as administrative burden within government benefit programs, and so by administrative burden, I mean you know the sorts of hassles and challenges people face when interacting with the government program. You know, having to wait a long time on the phone, having to fill out these really complicated forms, trying to minimize that. It is really important to help improve participation. And that is true when it comes to SSA programs, it is true with SNAP, it is true with TANF, with a variety of, in a variety of contexts. And introduced a couple of, couple of points I wanted to highlight here with regards to SSI and also a little bit SSDI is that there is really great study done by Manasi Deshpande and Yue Li that looks at the closure of SSA field offices. This is before the Pandemic but looking at how the closure of these field offices led to, you know, that makes it harder for

people to apply for benefits and that led to big reductions in applications. And by making it more difficult, you know, made it harder for people to apply, they didn't apply as much. And that was even true in kind of neighboring counties, where the kind of added congestion that might have occurred, and just that there is longer wait times to be at these field offices and go through the application process, also made it harder to reduce applications. When SSDI kind of shifted to online applications, a couple of researchers, Michel Grosz, Stephanie Rennane and Andrew Foote found that, that giving this online option made it easier for people to apply, and more people applied to SSDI. And so, I think in designing you know updates, outreach like making basically things that can help make it easier and more streamline for people to engage in that, minimizes this administrative burden.

>> Mike, you mentioned SNAP and the things like that too. You, Mallory, may have some ideas about, you know, is, SNAP is probably a lot easier to apply to, apply for than SSI? Is that an accurate statement? And what does that mean?

>> So, I am not sure, I would imagine that, yes, SNAP is probably much easier to apply for than SSI. I haven't assisted families with the SNAP application in the past, but I have never had a family reach out and say they were having difficulty completing a SNAP application, and I definitely have had that with SSI applications.

>> So, moving to a somewhat different topic, so how would increasing some of the requirements for SSI, the resources, threshold, for example, or other ways of evaluating in-kind

support and maintenance, potentially affect qualifying for a child of SSI? Mike, do you have some thoughts on this one?

>> So, you know the SSI resource limit is \$2,000 for an individual, or \$3,000 for a couple. And that number has not changed since 1989. And so, if you look at the \$2,000 asset limit today, kind of in 1989, that is the equivalent of almost \$5,000. So just mechanically there, you know, the amount of resources and assets that people can have and still qualify is substantially lower. Because, again, it would be the equivalent of having \$5,000 in assets today as opposed to \$2,000 in assets, just if it was allowed to go up with inflation. So, one thing that has been introduced to try to address this is ABLE accounts. And these are accounts that allow people with disabilities who have an age of onset under age 26 to save money in an account that is intended to be used for sort of any broad disability related purposes. And up to \$100,000 in an ABLE account, is exempt from this SSI resource limit. But despite this, there is very limited take up of ABLE accounts in particularly amongst SSI recipients. And so, you know, it looks like some research says roughly one percent of SSI recipients who are eligible you know take up ABLE accounts. You know Jeff Hemmeter has some good research on this, that has been looking at some of the state variation, and we will hear from him a little bit later today. And one of the things that we're doing in some research is trying to understand what are the barriers to take up. And, in particular, looking at you know the role that limited knowledge plays, the people just don't know about ABLE accounts. The role that these administrative burdens I just referred to play, and that maybe it is either difficult to sign up or maybe people misunderstand some of the rules, and you know may still, even though hundred thousand dollars is exempt, they may

not realize that, and they still fear that it is going to affect their benefits. And finally, because this is you know looking at SSI recipients, these are people with limited income and resources. They may not, they may just not have the resources to save. And so, some of our earlier research is finding that all three of those barriers play a big role. Then I think there is a question of you know ABLE is nice because, one thing that it allows people to develop and promote financial security and avoid this asset limit. A simpler way to do that would be to just raise the asset limit. But then, of course, there is tradeoffs with there too. And sort of what are the goals? Because you can imagine by allowing, having a higher asset limit, more people would qualify, people could maybe build some more financial resources, but a nice thing about an ABLE account is that, that money is also sort of safeguarded for people with disabilities in a way that it has to be used for a disability related purpose. And so, you know I think, thinking about this, helping people to potentially achieve and promote financial security while allowing them to maintain these critical benefits is really important to think about.

>> I think you said that the '89 resource threshold makes very little sense in 2023. Then that obviously is a source, a barrier, as it's applied or as it's thought through. And that is just a sort of low hanging fruit that ought to be raised substantially. You have also talked about the ABLE strategy, which not all households will take benefit of, but it does provide some benefits for families who would like to make use of that benefit as another strategy for keeping the financing in such a way, that the young person can still be eligible and receive childhood SSI. So, I think you just raised quite a few interesting potential barriers that do make it more difficult for

individuals to apply or qualify. How about the rest of you? MaryAnn, do you have some thoughts here too?

>> I do. And it comes from being out in people's homes with early access as well as having IEP meetings out there. In a rural state, our internet connection varies greatly. And we're talking about families that may not even be able to afford home internet. So, they don't have access to that, the high-speed part is why I'm actually in here today. In my house, I only have you know 20, is the highest I can get, high speed is 60 to 100. So, if we are asking, acting to try and increase internet, and other types of barriers, we have to remember that it isn't universal. It isn't like everybody lives in a large city and can access those types of resources. The other thing too is that families are consumers of the medical system. They don't always understand how everything fits together. They don't understand some of the questions on the questionnaire. It is asking a lot of a family to explain those in detail, and I think that is a huge barrier for families.

>> Amy, what are your thoughts in this area? What does -- that is very helpful, MaryAnn, since both the issue of recognizing broadband access and the real difficulties many families face and trying to understand the materials they are supposed to provide.

>> So, on my end, having worked with disabled youth who are in foster care, the asset cap presents some additional barriers to young people who are either going to go home to their families after spending time in care or age-out without having been adopted or reached any kind of permanency. And really it is well reflected in a client that I had 20 years ago at Legal Aid,

a young woman who was about to age out of care, who had already been accepted to college, and had saved money for years, working in a deli, and put money in a savings account. And she came to me while she was emancipating, because she said that she went to her bank to withdraw her tuition deposit and the bank said her assets had been frozen by the state where I was representing her. And she said there must be a mistake here. And it turns out in fact that she had been diagnosed with PTSD after, because of the circumstances of her removal and was unaware that she was ever receiving benefits. And in fact, the state froze her savings account, so that she didn't exceed the asset cap in order to preserve her eligibility for these benefits she never knew she was getting. And as a result, she couldn't enroll in college, she had to defer her plans, which certainly isn't the result that we are looking for. So, when we are talking about the asset cap as it relates to young people, who are already facing enormous barriers, when they age out either at 18 and in many states young people can stay in care until they are 20, 21, even 23 in some states, the average American family spends about \$50,000 on their children between 18 and 26 years of age. And these young people will, will leave with none of that support. So, it's, it's really important that their benefits be conserved, and that they be allowed to save and accrue assets in excess of that cap to give them an opportunity for self-sufficiency.

>> Dave, do you have some thoughts in this area too?

>> Yeah, thanks, James. I'm going to reiterate some of the things that MaryAnn had said and just put it really into the local context. Like one of the things that she had noted is that there are differentials in resources in terms of how people can apply for SSI, and those differentials

are not only the person's resources, but it is the environment in which the person lives. And I think it is really important as we think about SSI, and especially as we, and as SSA considers outreach to vulnerable populations which is a big initiative, is to really consider the, what I'll call the ecosystem of which SSI resides, which it interacts with special education programs, Medicaid, voc rehab programs, differences in terms of advocacy networks. And this becomes all really important in thinking about the resource to apply for SSI. And SSI is a very known quantity in some areas and some counties. If you map it out, you will see SSI participation is much higher in different areas in Pennsylvania, along the Appalachian Trail. It is virtually, I should say it is not virtually, but it is far lower participation rates in other areas, and a lot of that sort of gets to how well is SSI connected to the other set of safety net programs in the area. And all of this plays into sort of the efficiency in how you do outreach. And admittedly, I have sort of biases that if you want to do that types of outreach, do it efficiently by targeting certain areas.

>> Great. Mallory, do you have some final comments in this area?

>> Sure, I have a couple of additional thoughts. So, the families I spoke with and the families I worked with, often have, and this was already touched on briefly, but you know a really difficult time not only gathering the necessary medical documents, but then synthesizing that information and getting it into the actual application form. And so often times families may verbally be able to tell me these are all of the ways this disability is impacting my child, but when they go to write it on the form, they write, you know, a single sentence about how this

impact is, is occurring. And so, you know I think some of it, it can be -- because of variety of reasons, but I was speaking to one parent, and she was telling me, you know, she was like, I am scarred by the SSI application process. And she's like, and it has been a long time since I applied. She had, you know, she found out when her daughter was nine months old, that her daughter was diagnosed with sickle cell disease. And she was saying, she was you know a young mother with multiple other young kids. She was trying to navigate a new diagnosis, a new medical system, you know, multiple doctors, multiple specialists. Her daughter was hospitalized for lengthy intervals on a pretty regular basis. And so, she was like on top of that, I'm trying to deal with gathering all of this medical information, getting it into an SSI application, and then I'm having to, you know, go in for appointments, and having to you know just really having a really difficult time getting this application through. She, you know, she was rushing through the application, so she said I wasn't as thorough as I probably should have been, and so the application was denied, even though you know it was a situation where it was probably very clear that the child needed SSI benefits. And so, I think that is one thing to keep in mind is that families, no matter the income level, have a lot going on. And particularly some low-income families, you know, may have even additional, additional barriers happening that they need to deal with, you know, giving transportation to go to and from SSA offices, maybe not having paid time off of work, to be able to call during business hours and stay on hold for a while sometimes. And so, you know, I think that that was the main, the main other piece of input that I had.

>> Thanks, Mallory. I think the group is sort of saying, there are lots of ways that there are barriers right now making it difficult to apply. As complex diverse set of information that needs

to be put into the application, it takes a deal of work from our families to gather that information effectively, so it is really complex for families who may often be poorly resourced and have very, very limited time because they spend a lot of time on other things that they really must attend to. So, there are some real issues about making it work and then there are some special issues about how to connect this with other resources effectively or not. So, there's been a substantial decrease in childhood SSI participation since the mid 2010's. I was involved in a report from the National Academy of Sciences somewhere around that time which looked at the rates of mental health conditions among children receiving SSI, and it was one of the several studies that showed pretty clearly that in fact there were many more children in the United States who should be eligible both financially and diagnostically for SSI based on mental health conditions but weren't getting in. But I think the problem is it's actually gotten worse rather than better since then. What are your instincts into why? David, do you have any thoughts on this?

>> Yeah, and you know, full disclosure, Mike and I wrote a paper on this, and I know I'm going to overlap a little bit with some of his comments here. But, one of the things post-COVID, or I should say during COVID that happened, was we had the SSA field office closures occurring. Many public reports on, including national public radio of field office closures, caused substantial program declines which is absolutely 100% true. So global factors like this matter a lot as do changes in things like poverty rights, matter a lot. So the field office closures, really, really matter a lot. But if you're sort of like tuned into some of my earlier comments, the thing that I'm going to focus on a lot too, is what did COVID do? It disrupted networks. It disrupted schools. It disrupted primary care providers. It disrupted people from seeing other people who might be on SSI or -- it disrupted legal AIDS from going out and seeing other people. So all of those networks started to disintegrate alongside of COVID until you had this dual factor that was causing pretty substantial declines in SSI participation. And at the same time, you had other antipoverty programs that truthfully were easier to access, like the child care tax credit which has been noted as having very, very strong effects on poverty. But I do want to leave a part of

this for Mike who I know is going to talk about school closures, which relate to essentially the degradation of the networks throughout COVID and further plays into this regionality factor.

>> Mike.

>> Yes, I think your original question was about the broad decline kind of since 2014. So maybe let me start there.

>> That would be great. Thanks.

>> Yeah. And so, I think that there's a few big factors, kind of three that jump to mind, which relates to what Dave was saying. It's like kind of pre-pandemic. There was this -- the economy was broadly improving. And so, as you see poverty rates go down, also you see, you know, fewer people meeting that access and resource limit, then there's just going to be less participation. I think another big factor was the role of continuing disability reviews, CDRs, and there were -- so people who were on, children who were on SSI, you know, they have to have their benefits redetermined at age 18, but when they are children, they can have their benefits redetermined at a certain time period, based on what their expectation is of medical improvement. And that is somewhat -- had been more discretionary from SSA's -- in terms of like budget issues that they based. And so, between 2007 and 2010 there were only about 90,000 Continuing Disability Reviews each year on average, whereas between 2015 and 2018 there were over 200,000 each year. So that means that a lot more people were losing benefits, kind

of later in the decade who were on SSI. And we have some research that shows that has contributed to some of the broader trends that you have seen, and we're looking more into these CDRs to try to understand them in more detail. Another point that I want to add quickly is that health insurance really may play a big role here too; in that, during the mid, you know, 2014 is when most of the provisions of the ACA went into effect. Before that, again before, people were interested in children with disabilities have substantial medical needs, and we've done some research that shows that people do apply and end up receiving benefits primarily to get health insurance. And as more generous health insurance was made available through the ACA, that could potentially lead to less of a need for SSI among certain populations. So, I can pause there, or I can kind of talk a little about the school's piece too. If you want to talk more about COVID, I can come back to that. I realize I've been talking for a couple of minutes, so I want to pause.

>> So Mike, though, during COVID, of course, with the Public Health emergency people who were on Medicaid where they maintained their Medicaid without redeterminations until the end of the public health emergency, which was April 1 of this year, do you think that has some implications as well for the decline? I realize there were many other reasons during that period. Do you think that played a role?

>> I don't -- I'm not sure. It's not something that I necessarily have evidence on, but, I think that, you know, people who -- kind of people who are -- the generous, the generosity of Medicaid and that people could maintain their coverage, you know, that could in theory lead to

less, you know, less applications, but, you know we'll certainly see what happens in the future, but there's been big declines during this period. And one of the things that we do in this other paper is look at the role of schools specifically and show that, kind of where schools were closed, that there were lower rates of SSI applications and associated with remote learning. And that, you know. we do some back of the envelope calculations showing that these school closures can explain a pretty big percentage of the aggregate declines in the SSI applications during the COVID-19 pandemic. And just for context between April and September 2020 the kind of total applications for child SSI filed during that time was about 30% lower than it had been just one year before. And that's, kind of ignoring the broader declinment happening from 2014 through 2019. And so, these school closures definitely played a role. You know, Medicaid certainly could have potentially played a role, but I can't say too much on that.

>> Well, you raised the question of schools. Let's spend a little time together thinking through some of the issues on schools, getting information from schools the way schools can play roles in helping to identify households that might be eligible for SSI, et cetera. So, first of all, what are your thoughts about best practices for getting parent or guardian, for assistance during, I'm sorry, in the process of obtaining teacher questionnaires and individualized educational programs. MaryAnn, do you have some thoughts on this area?

>> Yes. The practice itself is a little challenging for parents in that we always give parents a copy of an IEP. They will always have access to that. States across the United States vary greatly in how parents can access that IEP. We are trying in our state to get parents' access electronically

if they want that. Other states you have to ask a teacher, go from there. Now if you are asking the teacher for an overnight P, we have to have a signed release of information under FERPA that allows the school to share anything in writing with an outside entity. And that's, you know, a big question I have. I didn't see a FERPA release on the site itself. That would be really helpful to have that because then it's a green light for the school. Oh, you've got a release, great, we're happy to do that. So, that's part of it. The other part I think really is -- it's a lot to ask a parent to do that. Parents are only -- unless they drop off their child at school, most have bus service that comes to pick up the child, takes them to school. There's very little contact unless it's an IEP meeting, an annual IEP meeting, or they are having an amendment meeting or something like that, parents really don't have a lot of context, or content, or actual access to the teacher themselves, and those things oftentimes will go back and forth in a backpack. And you'd be amazed how many things get lost in a backpack. So I think that's a barrier in and of itself. And there again if we could make that a direct portal that the school could access, get the FERPA release, I think it would become much easier.

>> There's a couple of strategies for making, getting those data somewhat more substantial.

What are your thoughts about how to provide some support or training for school administrators, educators to improve getting these kinds of information into the files?

MaryAnn?

>> I can tell you we are trained to death in schools. We have in-services. We have videos we have to watch. We have YouTube. The amount of training is overwhelming. Getting people to

comply is really challenging. So what I propose is what I think is the most helpful, or I found the most helpful when I create these handouts, because I do a lot of teaching as well for administrators, and that is to take the actual form itself, and in the white space below, put in an example of what needs to go there, do a summary, an example, and that way the tool itself is weighed beside what they are trying to do or on a computer screen, they literally can see what is asked of them, what needs to go in and it's a sample. And it's a great way to get compliance.

>> So let me just clarify. You're saying that school folks are trained up the wazoo and that -- but is that true about SSI, do those school folks know a lot about SSI?

>> They know nothing about it. And, I'm just saying that the time is very limited. Teachers get maybe, maybe an hour of planning time a week. The other part that I think is really important to understand here is that their systems are very confusing. You've got the medical system. You've got the education system. And then you have the government system. And all of those systems do not play nicely together. So it's really important to let everyone know what's available for resources. Guidance counselors, I don't think are used enough. School nurses, I don't think are used enough. School nurses could be a great avenue to explain not only SSI, but also waivers and Medicaid.

>> Do you think very many school nurses know much about SSI?

>> No, they do not. When I sit in IEP meetings, one of the first questions I ask every parent is are you -- do you have SSI, and have you looked at waivers? And the answers usually are no. So, I'm telling parents of children who are 10, 11 about a resource they should have had years ago.

>> So, this is potentially another strategy for improving households' access to SSI, to think through some of the key targets within the school systems there. Mike, do you have some thoughts on this area too?

>> Yeah, absolutely. And I think it's great to hear what you were saying MaryAnn. I mean not in terms of the lack of knowledge, of course, but I think that really ties to what we found -- well, like what we found when we did this study at schools. And that, it really seems like kind of knowledge referrals, information referral from school staff is really key in potentially driving why school closures played this, you know, school disclosures during the pandemic who led to this reduction in SSI applications. We found we sort of divided counties by whether they had a lot of school psychologists or not many school psychologists, and in the counties where there weren't school psychologists there was never going to be this identification and referral from school psychologists to SSI regardless of whether the school was remote. Instead, what we found is in these high school psychologists counties, when the schools went remote, without those services available there was this big decline. And so that really speaks to, you know, the way in which the in-person schooling experience helps people to learn about SSI. We have some other, you know, parts of that research that speaks to the role of networks as well. But, you know, I think it really reiterates that making sure that within schools because there's

special education, there's all these resources that are offered to students. That can be a really effective way to conduct outreach, to make sure that school psychologists know about and are aware of these programs, as well as other school staff are aware of SSI and we know kind of when and how to potentially make a referral if the student and their family would benefit from SSI.

>> So I think there's a lot of questions about the current strategies SSA uses to gather information from different sources and the kinds of materials they provide. So, for example, the SSA forms that might be used to get information from schools or, the issues in getting third-party activities to daily living questionnaires. Are there ways that SSA could get these forms better? Dave, you want to try that one?

>> Yep. And I'm going to pick on a specific form and if you're following along at home you can just Google this SSA form 5665 Teacher Questionnaire. And when you look at this form, it's very narrative in base. It explains why the information is needed, why it's not redundant of IDEA and why they need to respond even if they don't think the child is disabled. But, it's more narrative in nature than asking a busy teacher to complete this. So, they may either ignore or haphazardly complete because it's not an essential part of their job or they may not understand how it's part of their job. So I think that this is like the type of example of a form that can be tested. And I would be a little -- I hate to say I know all the answers on this call right now of how to revise, but some principles around revising the form are: One, shorten the form. Two, provide the information online. Three, make it objective and assess [inaudible] like can a

teacher provide things relatively quickly, such as is the child in special education? Are there grades?

>> And four, when possible, use information from existing forms, like IDEA forms, and that way the information is much more streamlined from what the teacher is usually using to what SSA needs. And, above all, test, test, test, test, because, once you've seen one school you've seen one school. So, it's really important to understand how teachers experience this form, not only like what the form needs to be from a compliance standpoint from SSA.

>> So I think that is very helpful, and you know, there are a number of other forms that SSA has used for getting information in a relatively systematic way. And I mentioned before the activities -- living questionnaires in some cases. Some of the data that's gathered from the mental health practitioners or psychologists, based on evaluations, some of the health-related information, is there some approach that SSA ought to take to streamlining these? I'm hearing a lot of suggestions that a lot of this ought to be available online. That seems to be pretty clear. Although we have also heard from some families that it won't work. But let's move beyond the sort of online question to what other questionnaires are there that are used that might be made substantially better? I don't know, Mallory, if you have some ideas here.

>> I don't really have thoughts necessarily to add to specific questionnaires, but think the overall process, a lot of the school staff I spoke with felt like they were providing the information via the individualized education program, via other documents, and then were also

being asked to fill out redundant information on very lengthy forms. And so I think their thought process was if we are sending the IEP, why are we also having to complete these very lengthy forms with the same information that is on the IEP? You know, and the forms typically, you know, they are saying take on average of probably about two hours to complete. One IEP [inaudible] actually sent me a picture the other morning to prove her point that anytime she sees the SSA envelopes come in the mail, she's like my heart drops because I know I've lost two hours of my day plus, because I have to gather all of the relevant documents and then regurgitate that information onto an SSA form. So I think finding a way to make those forms, and I know this is the big pie-in-the-sky answer, right, finding a way to make those forms less lengthy and then also not having school staff have to rewrite information that they are already submitting.

>> So MaryAnn, you've given us some ideas so far. Are there other thoughts about SSA forms and strategies for getting information?

>> David landed on it beautifully. That teacher form is not [inaudible] and it really needs a revision. The other thing I think might be helpful to the group as a whole, I have written a couple of chapters on special education across the United States and the IEP varies so greatly. If you've looked at IEPs they look very, very different. Very few of them actually incorporate the medical. Our kids that have complex medical conditions, very little of that is incorporated into IEPs. So I think it's important that we get a better handle on the medical and allow the teachers to go through the IEP, communicate the educational piece.

>> Makes sense. Do you or others in this group have ideas other than improve that medical information, that comes from the health care sector?

>> I'll take that, MaryAnn, if you want to think about it for a second.

>> So one of the things I would like to see done a lot more is use electronic medical records.

That's how we are moving in the country to disseminate information, yet we are still stuck in a lot of paper narrative forms. And when you think about one of SSA's goals is to modernize technology, using things like an app and allowing people to kind of see sort of like the beginning of their application to the end of their application and to request information through the app in ways that can go through a medical provider, is a way to get electronic medical records, perhaps, potentially in a more streamlined fashion. It's not a panacea because everybody has got different medical records, so it doesn't always work perfectly. But you might have more success in gaining information, particularly from providers who are used to sending information. I mean, providers are now doing things like de-consultations where they are sending information from primary care providers to specialty clinics. So this type of evolution towards where medical providers are, my answer here is a lot of the same as the teachers, which is I want to meet the teachers where they are at and really streamline the form and make sure we don't burden their time. I want to do the same for medical providers, particularly if we are not paying them or if we're paying a consultative examination that the information that we're asking is commensurate with the amount that we are willing to pay for the information. I

think that those are critical things. So EHR is definitely one of the places to go, but there are many others.

>> Yes. So the EHR has some strengths and weaknesses. As you mentioned they vary from place to place. There's a modern amount of consolidation in the market relating to children and youth around one product and it may be that there will be a way to really work with that vendor to come up with a strategy for providing information systematically that would work in the health care arena as well. Dave, while I have you, do you have some thoughts about improving the quality of the evidence relating specifically to defining children's impairments or categorizing, or sizing?

>> Yeah, this is a challenging one because, you know, one of the first places that I want to start is how much is SSA going to pay to obtain this information. Are they going to pay to obtain sort of customized reports from a medical provider who has to provide this information? So if that is really, really, critical, I think it's one of the things to really look into is taking a look at, for example, the consultative examination process when a person has to be ordered to provide additional medical evidence, what are those systems looking like? There's wide variations in consultative examinations across states. There's even variations in the forms that SSA uses in these different states. So, making assessments in terms of what is the content and the quality that they are getting, and also being very precise of like what type of information they needed because you might not need to fill out a full consultative examination to make a disability determination. It's possible the examiner might need only very targeted information. So trying

to get a little bit more streamlined in using technology to figure out what parts of the application need to be enhanced as opposed to sort of reordering a medical record and sort of building, you know, pages and pages of medical documentation. If you look at some of these application records they are extraordinarily long, they are very text based. So things that can do that I think would greatly enhance the type of medical information provided as well as the willingness for those who have to provide that information to provide it.

>> Amy, you've provided us already a good deal of very helpful thinking about SSI beneficiaries in foster care, some of the issues about representative payees and some of the strategies for potentially improving accountability of representative payees, improving the understanding of people in foster care about whether they are getting benefits or not. Do you have some other thoughts you wanted to share about strategies to improve the issue of SSI beneficiaries in foster care and after?

>> Yeah, thank you. I think the foundational issue for me as an attorney comes down to notice and due process. It's really crazy to think of a whole class of young people who are receiving benefits for many years and who themselves, nor their parents, ever know about it. So I feel like that's the first thing that's really important to address, and of course from a constitutional perspective we shouldn't be taking people's property without due process. But also, from the perspective of having an opportunity to have a say in what that child needs and what is in their best interest, and of course that can be done in court by the child's attorney or the child's guardian ad litem if they live in one of the ten states that don't give foster kids attorneys. So

that's really critical as a foundational issue. Frankly, judges in child welfare cases don't know the child is getting benefits either. Nobody knows. Their benefits are applied for and intercepted in back finance offices of child welfare departments. So that's a foundational issue is being able to engage through fair notice and due process. And as I keep reminding agencies, SSA has a payee preference list for children receiving benefits. And it's really supposed to go in order of who cares most about the child. You know, there are parents on there, relatives, and other trusted adults in the child's life. And organizational rep payees, like foster care agencies, are the very last on the list, yet they are automatically approved by SSA for all children in care. And the agencies that are applying only recommend themselves as potential payees. So SSA doesn't have a chance to appoint anybody who actually cares about the child to serve as the rep payee and isn't actually even following their own rules about making sure they are exploring all of the options that would best serve the child. So that's really critical because I have yet to meet a grandparent or aunt or uncle who would decide that the best use of that child's SSI money is to pay the agency back for their room and board instead of using the money for other supports and services or to save it for the child's future needs. So those are two things. And, you know at the end of the day, as a young person said to me recently, my benefits are supposed to benefit me and right now the only entity being benefited by children's disability benefits when they are in foster care are foster care fiscal departments. So it's just really critical that we/us as SSA direct make specific individualized determinations in each case about what this child's needs are, what services and supports do they require, and how could their benefits be used to address unmet needs or conserved for future needs.

>> So, do you have a thought about mechanisms SSA might consider to put into place to sort of work out rep payees, for example, to clarify the questions you're raising?

>> Yeah, and I've submitted some suggestions and ideas to SSA staff, and I know that they are considering those to put out some new guidance and rules, hopefully, in collaboration with the Department of Health and Human Services which runs our foster care program in the country. The EPRS form that is used to identify potential rep payees is supposed to include information on all of the entities that could serve so SSA can make an informed decision about who to appoint. And agencies are routinely appointing themselves which is explicitly prohibited. So there needs to be a better job on their part of providing more information and on SSA's part in making sure they actually know who's available to serve. You know, little known fact, a lot of kids in care, their parents can still serve as the rep payee, as long as their rights haven't been terminated. And not only are they not being given a chance to, they're actually -- they have no idea their kids are getting benefits while they're in care either, unless those benefits are transferred with the child when they come back home. So that's one really important piece. And the other important piece is just a clarification in the POMS. There's some places in POMS that talk about engaging the child's legal guardian. And there are other places that talk about engaging the child's legal representative. Those are two very different things in the life of a foster child because the legal guardian of a child in state care is the agency, the very agency that's applied for and is pocketing their benefits. The legal representative has an independent interest in that child's rights and in their future and making sure they're getting what they need.

So that would be a really helpful clarification make, to make sure that the intention of SSA in providing these benefits actually ends up as intended to address the child's needs.

>> Thanks very much for a very helpful suggestion. I'm glad that SSA is considering them now. Could we spend a few minutes just understanding something about the outcomes of former childhood adolescent SSI recipients? People have been interested in this question quite a bit. Dave, I know you've worked on it. We've talked about this in the past.

>> Yeah. Thank you very much for this question. It's one of my favorites, but it's also one of the most difficult to cover because many former child SSI recipients face challenges in transitioning to adulthood. They experience high dropout rates, unmet healthcare needs, and low employment rights. They also have very high risk of incarceration. And so when you think about child SSI recipients, you can almost think that this is a group that society really should think about investing in. This is not a political statement. I suspect both sides of the aisle could sort of agree on this point, both investing in the social outcomes of youth but also, when those social outcomes turn poorly, they tend to be very costly for society. So when we think about issues of access, which is a lot of the things that we've been talking about today, access, and how to gather medical evidence, it's not just for initial access. It's for continuing access because, as we've been describing earlier, there's been a lot of changes in recent years, particularly with Continuing Disability Reviews and what happens to those children filing those reviews. So that is a key issue. So one sort of thing that Congress could do is start thinking about how to develop interventions that really focus on how do I move my child into adulthood. And for any parent

that has a child, we all think of this issue, what is my teenager going to do into adulthood. And to be encumbered with we might lose our income stream because of this can really potentially change like how both the child gets resources and how the parent responds in ways that are not productive. And so thinking about ways that we can make the system much more friendly to transition to adulthood, I think is key. And there's a number of sort of things we could do. But one simple thing that I think can be done is just simply not count the earnings of child recipients. There are a whole bunch of special work incentives so to speak. But at the end of the day, for a child recipient, when they earn income, they not only report that to the IRS. They have to report that to SSA. That's an extra step that people that are not on disability programs have to take just to work which we know from the literature, essentially these early employment experiences are fundamental not only to long-term transitions but to developing social connections and really addressing issues with isolation. So thinking about some of these issues much more globally in terms of how to improve outcomes of former child SSI recipients, I think, is paramount to both access as well as sort of providing continuing access of what happens to a child if we do have a cessation. And should somebody be thinking about that child. And all of the evidence suggests yes they should, because the outcomes, particularly on the paper that Manasi Deshpande wrote, is that they're very, very poor. And income volatility follows you through a lifetime.

>> So you're talking -- David, I hear two or three things. One is to improve the whole issue of transition. And are there barriers to transition in the current SSI program?

>> Yeah. I think there are barriers. One of them is simply that you have to report your earnings and your eligibility. And so, whether this be the parent or the child, if you work over a certain threshold, you face an issue such as an overpayment. And if you receive an overpayment, you can completely disrupt the income of the entire family. And so we're not only just talking about the parent and the child. We might also be talking about other children in the household. So that is, I think, one important issue. I think sort of a second issue to consider is just the age 18 redetermination itself, asking how is that consistent with other aspects of our safety net. And one sort of low hanging fruit is sort of thinking about how does this play into IDEA where the age of IDEA ends at age 21 but we're doing redeterminations at age 18? And so, I think that there is some ideas that, when we can think more holistically. About the child -- because a lot of times, we think about these programs as one-off, and they become siloed. But for the child, they experience these programs holistically. So those are some of the barriers. And some of the solutions that I've seen hold promise is, when we look at some of these employment interventions that have been tested, whether it be through promise or the youth transition demonstration or even outside demonstrations, what we find is that there are some effects, particularly during the demonstration period where we can increase the employment outcomes of people that are participating, and we can align them to employment. But it's hard to maintain those effects longer term, particularly after these demos end. But there are some potential promising avenues when the interventions provide supports that are not in the youth's environment. So for example, if the youth has limited schools or access to vocational rehabilitation or employment services, it's very hard to move the needle for that youth in terms of trying to improve employment outcomes. But if you give that person an education or

employment opportunity, whether it be in a residential facility like Job Corps or Year Up or those types of places, there's potential by providing services that are not in the youth's environment that they have potential to increase their long-term outcomes. And those are avenues that I think certainly could be tested going forward and thinking about how to develop better connections to provide access for youth. And I should note, not all these changes would be beneficial to all youth. Some youth will, despite our best efforts, might not want to be employed or cannot be employed. It's really just providing those options so we're not losing many youths because that's what's happening as many youth are falling into issues with juvenile justice.

>> Mike, you have some thoughts about how to otherwise help with this transition?

>> Piggybacking a lot on what Dave said and just building on some of those points, you know, this period of transition is one in which youth go from kind of primarily accessing their supports and services through school to one in which there's a very fragmented safety net that relies on vocational rehabilitation, various other types of employment supports and health supports. And that makes it really difficult to navigate. And so we've seen, in something like Promise, trying to think about that a little bit more carefully and trying to promote interagency collaboration. And there are ways in which Promise was successful in promoting, you know, employment outcomes. But it was also, you know, each of the individual programs had sort of their own challenges as well. Where overall though employment rates did go up for the youth who got these services. And another big challenge here is, as Dave said, the age 18 redetermination.

And there's some really interesting research that shows people and families don't expect and understand how likely it is that they're going to lose benefits at the age 18 redetermination. When you ask families -- like I think the most common response, what's the probability that my child is going to lose benefits at this age 18 redetermination, more than half of families say they're not going to, there is no chance. But in reality, 60 to 70% of people, especially those with mental conditions, which is the majority of youth SSI recipients, are going to lose benefits at the age 18 redetermination. And planning for that presumably can only help with the transition. Not being aware, not noticing that, you know, it can't help. Even if -- you know, one interesting finding from that paper is that parents didn't change their human capital investment decisions when they learned that in fact the probability was much higher than 0. But there's -- I mean, all of these complex systems and the way they interact, they contribute to these really limited and poor outcomes for youth who were on SSI, as Dave noted.

>> So I think we're hearing both of you saying similar things about trying to get a variety of services in place at the time of transition, try to help young people in their households understand what the age 18 redetermination is and so forth. Is age 18 the right age?

>> Who's that a question to?

>> I don't know. Dave, you want to try?

>> I'll give that a try. I mean, I think that's a complicated question. That was the age set at welfare reform. And that was the age when people become adults in the SSI program. So that was part of the rationale. But I think there's an open question of whether it's the right age. And it's hard for me to say that it is the right age because it's never been tested. This is a policy that was developed and implemented. There wasn't a real strong rationale that it should be age 18, 19, 20. There are a whole bunch of psychological studies that say the human brain doesn't fully evolve until age 25. I find that reassuring as having a child that's 20 years old and hoping that that brain will continue to evolve. But it is -- when you think about that, you think about people taking risks and you think about how they're approaching their employment situation. I mean, I can say that this is a particular area that needs to be tested, in large part because there's inconsistency in federal regulation. So this isn't even the world according to Dave. This is the world according to how our different systems operate. So I think from that standpoint, this should be either tested or changed or looked at policy options. And you know from the other standpoint of like how youth's brains development, this is a very, very big issue. And thinking about how can we best craft programs around youth as opposed to complaints, I think, is a very, very big issue. And hopefully, MaryAnn, I didn't cut you off.

>> No. That's fine. What I wanted to talk about was transition. You raise a wonderful point, David, which is that IDEA is designed to help make that transition to voc rehab, then into the employment world. Every state is a little different in how they set their transition; the age they set it, how they do it, how they go about it. I really believe that would be a wonderful improvement, like you said, to join together those organizations that help children have the

same age. Have it all be 21. That makes the most sense. And then they would be out of the school system. No parent looks forward to their child aging out of the system, because the adult system just isn't the same quality.

>> I would just add, as a clinician, we know age 18 is an extraordinarily complicated age in any young person. There are many, many issues to deal with developmentally, kind of a complicated one. And you know, we can argue for other ages in the area of transition. But let's move on to some other questions, if we could, and maybe get back a little bit to some questions from the audience today. So do and should schools provide information to parents and guardians about childhood SSI? I think, Mallory, you may have some ideas here.

>> I do. Practically, some schools are great about providing this information. Other schools don't really mention it at all. So you know, in my mind, I always think it would be great for, you know, during IEP meetings and during section 504 meetings if school teams had a super brief one pager. Parents get super overwhelmed. So a really brief one pager basically saying, hey, SSI exists, here's where to go to apply for it, and here's a point of contact within the school, you know, if you have additional questions and would like to talk through this. So I think that would be really great. You know, and I would err on the side of giving this to parents every year. You know, I know they get a lot of forms in IEP meetings and 504 meetings. But giving this to parents on an annual basis just as a quick reminder to say hey, this exists, here are some resources and ways that you can learn more.

>> MaryAnn, any thoughts?

>> Yes. I think schools should be brought in. But I keep trying to get us back to school nurses. You know, we talk about involving special ed teachers. But a lot of our kids on SSI have medical conditions. And the school nurse is an ideal person to link into that, to help explain the condition. As part of an evaluation to determine eligibility for special education services, we do evaluations that include health. A lot of those medical records are already found in the health office. And so it's really important to make sure that we're linking in school nurses, asking them questions, and giving them information so that they can be a source for the parent as well.

>> Great. Forgive me, I'm reading some of the questions from the group -- from the audience. What can SSA do to change to address the decline in childhood SSI applications over the past two years? I think, Mike, Dave, you've both spoken about that and the fact that there were all sorts of institutional changes or closures that limited young people's and family's access to information versus the data. Are they open enough now? Or are there other things that SSA should be doing? Mike, you want to try that?

>> Yeah. I mean I think that leveraging networks is something that is so important. And schools can be that network. I think you raised a really good point, should schools be providing information to families? Yes. That's a way that schools -- that families can learn about this. There are other informal networks where, you know, we saw that during the pandemic, some of the biggest declines in applications were from the places that had higher SSI participation to

begin with. So those networks that existed really broke down when kind of everything shut down. Something that SSA has been doing is, with these vulnerable population liaisons, they're trying to find ways to promote and make sure that kind of vulnerable populations are learning about this program and have the assistance they need to complete the application process. And that's a really important step in thinking about, really creatively, where to target those resources. It is so important. To make sure that they're drawing on evidence, drawing on like where is SSI least -- kind of where the -- where are the potentially eligible people specifically? And that's actually a good tie to some other research that we're doing where we're looking at kind of using Medicaid data and using health claims to really try to understand who are people that we think might be eligible but are not based on their kind of existing -- what are their health experiences. And, you know, it's pretty early stuff, but like you can imagine trying to use these resources to get to those specific people, whether it's in their communities, kind of thinking about what are the characteristics, you know, what types of healthcare providers are they using specifically, because we can see that in our data. Those sorts of efforts and using evidence, using data to try to get to the people who are most vulnerable and most in need of SSI is going to be critical as we come out of this period where applications have been declining so much.

>> Thanks. Any other ideas from the rest of the group in this area?

>> You know, just to underscore using data to identify the best places for outreach. And SSA is already doing some of that, to look at where the caseloads have declined. But there are a few

other places that I would sort of like really target. I want to know what's happening to the youth that have been ceased from the Continuing Disability Reviews over the past ten years. A huge spike up from 2015. That's an important group to understand what's going on. There's been a lot about how to sort of target outreach. But I'm going to sort of also return to -- forms matter a lot. And as you look at the work and you think about that process of like how to help people with those forms, there are different areas with better systems to help people with SSI forms. And if you had to fill out the SSI application on your own, it's a lot of work. And it might even be too daunting. And that's hard for a program whose goal is to serve low-income families with disabilities. So what do we do with that? Well, where are there areas where there are good networks? Can we use those networks, using things like Zoom or MS Teams, whatever platform you want, to connect people in these different offices? When you talk to some of these legal aid folks, they are amazing in terms of understanding the landscape, the person. But perhaps most importantly, about meeting where the person is because a lot of times when you're filling out an SSI application, it's not so neat. You might be in a homeless shelter dealing with somebody that has bipolar depression who is upset with the government for whatever reason there is. And so, understanding that context and creating systems and frameworks to allow people not to just be in their localized context to apply. And SSA has online applications, but I'm talking about like really linking them with people, because it's people talking with people where innovation matters.

>> Thanks. Really good advice. I have a few questions that really relate a bit to some of the medical issues here. I'm not sure if anyone wants to deal with that. One is the question about

are there recommendations to help enhance the requirement to ensure children on SSI receive medically necessary and available treatment to assist in their function, development, general health, and wellbeing? Somewhat controversial question. Anyone want to talk about that? Or I could go on to others.

>> I will try to take this one, at the risk of being controversial. I was one that once thought that mandates might be important. But as learning from dealing directly with the population and kind of understanding their needs, a one-size-fits-all framework for particularly this population of requiring medical necessities could backfire in ways that it feels like government is controlling your medical and telling you exactly what to do and how to do it in ways that a patient might not like, and a doctor may not order. So in terms of having it sort of as a requirement, it makes me feel uncomfortable is the best way to describe it.

>> I would also chime in on that as well that it's difficult to have an entity that is providing service also be a watchdog and do that self-regulation and self-monitoring. What I have always said is that there should be a review process that looks at a bigger picture. What would that review process be? That's a really good question because, as I look at the care provided for the hundreds of kids that I've seen, some do get better care than others. Some do get more resources than others. And it's usually those that have the parents that are willing to advocate are the ones that get the best services. How do we even that out so that all kids get what they need? That's my question.

>> Thanks. That's a good thought and an issue in this particular area. And I think, at this point, I'm going to thank this incredible panel for the amazing ideas and thoughts that you guys have provided today. I certainly have learned a lot. And I hope that the team at SSA has also learned a lot here. I think we really want to thank you so much for the excellent, excellent time and effort. I wish we could continue this discussion all afternoon. At this point, I want to transfer this to Jeff Hammeter who's going to close the session.

>> Thank you. Thank you, Dr. Perrin and all the panelists today. This was an excellent discussion. I also want to thank all of the participants today. As someone who's been working on research and conducting research on youth, children, and SSI for many years, the discussion really brought together a lot of themes. As discussed, these children tend to have poor adult outcomes with a high social cost. So the role of access to potentially helpful services and supports, including SSI, is an important issue to understand. I want to highlight just a few of the ideas that were discussed today. Many of the panelists touched upon the difficulty of SSA's forums. And I think many of them really touched upon the need to move past just thinking about the minimum programmatic information and SSA technician needs but about how the people using the forms, filling out the forms, the claimants, the parents, the representative payees, the teachers, the medical professionals and others, you know, how they will understand the forms so that the information that a technician gets is correct and also sufficient. Other panelists noted local barriers, internet access was mentioned for one. But also that although the SSI program is a federal program, it's important to remember that the U.S. is a large country with a lot of differences. And there may not be a one size fits all with respect to

resources. Many related programs are run by the states. So there is a mosaic of policies that interact with SSI. You definitely heard about certain ones in the education system, for example. Other discussions -- panelists mentioned many other barriers, some statutory such as the stagnant asset limit and the age 18 redetermination age, but also situational barriers such as access to transportation, long wait times, and commuting hours and access to records. Amy Harfeld discussed items that are really important in foster care; organizational representative payees and protecting the children's rights to their benefits. These are all significant items touching hundreds of thousands if not millions of children and families. Networks were mentioned a bit. And if you are part of a network, I would be remiss if I didn't mention, if you go to ssa.gov/youth or ssa.gov/schools or ssa.gov/third-party, there are a lot of resources that can be shared with different groups that might be something that could help address some of these. Some of them can be approved, potentially. And we would love to hear you. I do want to thank you all for being willing to discuss all these issues and for helping SSA better understand them as we prioritize what to address with its limited resources. And before we close today's forum, 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 the time to complete the evaluation. And it will help us improve and offer topics for future forums. This email will also include a link to the 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. Thank you again for joining us. And remember to join us for

part two of this conversation on Wednesday, May 17. Registration will open on Monday, May 1.

Please look for the email. 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, part one. Thank you for joining us and have a wonderful day.