nTIDE Deeper Dive: 5/17/2024

**Recorded Introduction:** Hello, and welcome everybody to the National Trends and Disability Employment. Or nTIDE Lunch and Learn Series. Just a few housekeeping items before we begin. Okay. This Webinar is being recorded. We will post an archive of each Webinar each month on our website at www.researchondisability.org/ntide This site will also provide copies of the presentations, the speakers bios, full transcripts, and other valuable resources.

As an attendee of this webinar, you are a viewer. To ask questions of the speakers, click on the Q&A box on your webinar screen and type your questions into the box. Speakers will review these questions and provide answers during the last section of the webinar. Some questions may be answered directly in the Q&A box. If you have any questions following this recording, please contact us at disability.statistics@UNH.edu Or toll free at 866-538-9521 for more information. Thanks for joining us. Enjoy today's webinar.

**Andrew Houtenville:** Hi everybody. This is Andrew Houtenville. Just a few notes. ASL interpreting and closed captioning are available to see interpreters in the gallery of speakers at the same time, we recommend using a computer or a laptop rather than a phone or a tablet. For closed captioning, there's a button to click on within Zoom, and also you can select either show the subtitles or view a running transcript down the side.

Just a little bit of a heads up in the future, probably over the summer some time, we're going to be testing out a switch from Zoom to Microsoft Teams as our webcast platform. And when the time comes, we'll help you if you need support in doing so, but also we want to hear from you as well about whether teams is working well for you. You know, it's just about budget savings for the university is really the only reason we're switching, but we've been with Zoom from almost the very beginning, 2013.

Okay. So a bit about the nTIDE deeper dive. It occurs noon Eastern on two weeks after the first Friday nTIDE, and it's a joint effort of the University of New Hampshire, Kessler Foundation, and the Association of University Centers on Disability AUCD. Each month, we take a deeper dive into a specific sub population within the population of disabilities, and we bring in a guest speaker that has something to say about that to provide some greater context.

And we have a colleague, Ankita Patnaik who is with us today from our colleagues, from our collaborators at Mathematica policy research. Actually, it's just Mathematica now. I've heard. So, today's introduction. We'll start with the introduction. Then I'll provide some review the nTIDE, the first Friday results, and then talk a bit of a deeper dive. And today, we're going to be going into youth and young adults. And then Ankita will be presenting and then we'll have open question and answers and get input from all of you in the field.

Okay. All right. So first Friday. These will be the updated data from April and currently this week, the May survey is in the field at the moment. So we don't have may numbers, but we have April numbers. And so this is the slide we usually show during the nTIDE lunch and learn on first Friday, so this is the March result if you've been on nTIDE before, you've seen this and we continually update this month to month. And this shows for people with disabilities, a decline after the great recession.

Employment usually lags behind economic growth or recessions and bottoming out at 24.1% in January 2014. There's a slow rise, and in fact, during 2016-17 and into 2018, there was a narrowing of the gap between people with and without disabilities, then it levels off in 2019, the pandemic comes in and the employment to population ratio, so the percentage of people with disabilities, 16 to 64 who are employed dropped from 31.7% to 26.3% during the COVID recession. COVID lockdown recession.

Then we see some relatively slow growth after that, as social distancing and economy starts reopening. But then really in 2021, we see a dramatic increase and that says the vaccine starts rolling out, and then continued growth. So people with disabilities pass the peak pass the pre pandemic peak in late 2021 and then almost consistently grown over the last couple of years. And we've been tracking this very closely with nTIDE. And, you know, I would say that the growth that we've seen pass the historic high back in the 2008 during the Great Recession and, it's been maybe leveling off more, and you'll see that for some of the other statistics we'll show.

The big contrast for people without disabilities is that people without disabilities only recently reached their pre pandemic peak, and were much slower to recover. It's been a much slower recovery and have really leveled off back to their seasonal. You'll see some sawtooth in these two lines, and that's typically related to seasonal, especially evident in the trend line for people without disabilities. So let's add in April, April, people without disabilities stayed exactly the same.

People with disabilities bounced back up. Some of the variation we're seeing, some of the sawtooth nature of it is that the sample of people with disabilities is smaller than the sample of people without disabilities. And Some of this will be sample variation from month to month to month, which is why we always used to look at the year prior, so we wouldn't have seasonal effects and this isn't yet seasonally adjusted. I think it was we've got enough data to do seasonal adjustment, but COVID really put that in the mix. All right. That's April.

So let's take a deeper dive. We had Andy Carhan from Cape Youth Project, a DOL Department of Labor ODP funded project out of the University of San Diego, University of California, San Diego and Andy Carhan. We're going to do that similar, but we're actually going to break it into more narrow groups to look at youth and young adults. And I'm going to do some comparisons to youth and adults without disabilities because if we see youth with disabilities improving, well, that could be true for youth without disabilities.

Perhaps it's just the youth labor markets, the labor markets that you adults are going into, so we want to make a comparison. I will be showing a ratio of the two similar to relative risk ratio if you're in the health fields. But basically taking the employment population of people without disabilities and dividing, sorry. With disabilities dividing by the employment population ratio without disabilities.

So we're going to do something a bit different in order to get and this is how the Department of Labor approaches it as well. When we're looking at smaller groups, they will basically take the 12 months and average them. Take the ones you saw above were monthly, and so we're going to take those and average each 12 month period. And I picked April to March because of the lockdown recession. Where we're going to if we had to span, say, the calendar year as the 12 month periods that we're going to average that dip during the great recession, the COVID recession, would be kind of muted being averaged out.

But having it having the slices be from April to March is really accentuates the COVID. And then we can talk about the first full 12 months past the lockdown first 12 months, second, 12 months, third, 12 month period past.

So we'll be able to do that as well. It kind of helps to think about 12 months past COVID outbreak, 24 months, 36 months. So this is the trend line the dimensions are different, the width of this line is different, but this is the same time period 2009/10-23/24. So these are really the freshest data we could get that uses this average approach. And so this is what you saw before the decline during, you know, a slow decline to around 2014, a slow increase up decline during COVID, and then a progression upward with a slight tapering off in the last 12 month period. That's people with disabilities. We can snap.

Now I'm going to snap in various age groups. So here's what I would call youth and young adult that is a focus this month. During the Great recession, there was quite a big drop for them, relative to all others with disabilities, and then a rise up and actually closing the gap. The population age is 16 to 64. We don't have onset information, so this is at any point the onset can occur. This is the smallest age group that we have because of the onset of disability with age. And so keep in mind that you'll see this we'll jump around a little bit more because it's a smaller group.

So if we add in 16 I'm sorry, 26 to 34, there's actually quite a substantial rise COVID, both the 16 to 24 and 25 to 34 recovered from COVID, 25 to 34, I'm going to struggle with those numbers, boy. You didn't really recover as fast, but actually did quite well even up until this past period. For 36 that should be 35. Sorry, everybody.

For 35, pay attention to the other sides. 35 to 44, again, a recovery, they took quite a bit longer to recover from the pandemic. They didn't hit the pre pandemic peak until after the first 12 month period. If we snap in ages 45 to 54. We see a similar pattern. And for those 55 to 64, I need to come up with names like this would be the near retirement age. The near retirement age, not a big decline during the COVID very stable employment, and that may be related to more senior positions and kind of leveling off in the last few months.

Again, young adults, youth and young adults doing pretty well. But the 25 to 34 year olds really doing quite well. But again, we need to compare this to the same group of age groups for people without disabilities because it could be just that this age group is doing really well, you know, it could be the natural movement, and we'll get there. So that's what we'll start doing.

We'll do the same chart for people without disabilities. Here's all the ages 16 to 64, snap the 16-24 year olds. You know, again, smoother lines, bigger sample size in large part will drive that. Don't have to worry as much about seasonal effects because this is a 12 month average.

And so luckily we have 12 month seasons, and we can see the decline. Again, a slow recovery and not really jumping past their pre COVID peak until recently. And so that's kind of a consistent story as we snap in more and more age groups that you know a slower recovery and only now about reaching a leveling off and reaching their pre pandemic peak.

Same for 35 to 44, 45 to 54, 55 to 64. All right. Now, let's just compare the two lines. It happens that I can keep the chart. I always try to keep the axis the same so that you're looking at the axes have shifted up and down, but they've had the same spread, and it happens I can put these on the same chart. So we have people without disabilities, people with disabilities, 16 to 64, and we can see consistent with what we've been talking about a slower recovery for those with disabilities, without disabilities and a tapering off and a good return past peaks past the COVID peak, and then a good growth, and then a little bit of tapering off in the last 12 months.

So that's the comparison. So what we can do is we can take the ratio of the two and look at the relative, it's not risk, the relative ratio of the two populations. And so this is the ratio of all ages. The dimensions of the vertical axis is a little different for this one I couldn't fit it in to the same stuff, and I didn't have time to adjust all the slides to fit it together. Okay. But all ages, you know, it's now up to 50%.

So how we would read this is this is proportions. So changing that to percentage is 50%. So the employment the employment of people with disabilities is about half that of people without disabilities, right. And so, you know, it was a low of around 30 That's probably around 37-37.5 and then pretty solid growth post pandemic, there's been a lot of research to understand that. I can talk a little bit more about that. Now we snap in the ratio for 16 to 24 year olds. Again, it's at all points higher for 16 to 24 year olds, and it's currently at about two thirds. The employment of people without Sorry.

The employment of people with disabilities is about two thirds that of people without disabilities 16 to 24. And it was at a low of around, you know, 47 and now it is at 67, 20 percentage points higher. That's a real nice result. It is growing faster than, you know, the overall population and you know, in some sense, you know, the COVID so there's going to be a question that's going to have to be answered, you know, once we get enough data. To what extent and certainly for the population, to what extent is the the post pandemic increases. Are the post pandemic increases just a continuation of a prior trend that's possible that some of it is true.

However, you know, there has been a substantial change in, we're remote work which and flexible work hours. So it's likely to be both. If we snap in 25 to 34 year olds, a similar pattern for them as well. 35 to 44, 45 to 54, and 55 to 64. And so one thing to, you know, kind of a summary, and I think this is my last slide. A summary of this is basically all people with disabilities when we break it down by age group. Benefited are doing well post COVID, and we're doing pretty well prior to COVID as well, and some groups are doing better.

So groups recovered from the lockdown recession faster. But all groups. And if you want to see more groupings, we did the same analysis with lots of different groups last mid month where veteran status rural status disability type, gender, race, ethnicity. And really, all groups have benefited post recession or post lockdown, some more than others, some faster than others.

In terms of a leveling off, that's probably the story that we'll be looking at in the next couple of years, is this going to level off or is it going to continue to grow? And I'm all for growing, you know. But that's kind of all I have to say. You know, if I have to think a little bit further, Ankita is going to talk about youth and young adults with autism, experiencing autism. You know, the one issue with looking at employment rates for youth and young adults, is some of them may be at school. And so you may say, oh, well, this is great.

They're really well employed. Well, that could be because they're more likely to be employed than be in school. And so if I was really going very, and I don't know if the monthly CPS allows me to look at whether they're currently enrolled or not, I don't think it does. But what I would want to do is kind of look at the share, look at the amount that they're also going to work in school and kind of look at the jointness of that pattern because, you know, you know, at first blush, it's like, Wow, that's great. They're doing great.

The youth and young adults are much more employed if they're, you know, with, you know, are more likely all relative than other age groups. But again, it may be because of schooling. That young adults youth and young adults without disabilities are in school, therefore have lower employment, relative to all the other ages. So I'll stop there. I'm going to turn it over to our colleague, Ankita Patnaik from Mathematica and take it away Ankita

**John O'Neill:** I'm going to take a minute to introduce her.

**Andrew Houtenville:** Oh, good. Thank you, John.

**John O'Neill:** Sure. Ankita is a senior director of research and evaluation at Mathematica. She leads several research projects focused on employment policy issues, especially for youth and young adults with disabilities. She directs the research support services for employment of young adults and for young adults On the autism spectrum on the autism spectrum project and also a feasibility study of respondent driven sampling to survey transition age youth. Ankita, I'll hand it over to you.

**Ankita Patnaik:** Thanks very much, John. Hi everyone. My name is Ankita. My pronouns are she and her. Very happy to be here today as part of the nTIDE webinar, to be sharing some findings and recent work around advancing opportunities for employment of young adults in the autism spectrum.

This is work that I've completed with my colleagues at Mathematica, including Paul Shadok, Marissa Shank and many others on our team, I'll start with the note that throughout my presentation, I'm going to be alternating between using person first and identity first language around autism, which reflects some of the mixed preferences within the autism community. Next slide, please. Okay. All right.

So everything I'm going to be talking about today is part of a project called the REYAAS Project. REYAAS stands for the very long project name that John just went through, Research Support Services for the Employment of Young Adults on the Autism Spectrum. We call it REYAAS for short.

This project is funded by the US Department of Labor's Office of Disability Employment Policy, also known as ODEP. It's a five year project. It began in 2021. We've been at it for three years, and we still have more than two years to go until the fall of 2026. The project focuses on young adults, defined as ages 16 to 28, who are on the autism spectrum. Okay.

The project has four overarching goals that bring together all of the different activities. The goals are to understand the various facilitators to employment for this population to identify ways to improve employment outcomes to highlight and fill gaps in what we know based on research and evidence and to suggest new activities that researchers and that government agencies can conduct to build more and higher quality evidence. Next slide, please. I think we might have gone one slide too far. Sorry. Back one slide. Well, there may be a slide missing. Okay. Apologies.

All right. Maybe I'll just talk through some of the context before we talk about the project activities. So you might be wondering why is this project focused on people on the autism spectrum in particular rather than a broader group of young adults with disabilities. Well there are several motivating factors. One of them is the size of this population.

So it's estimated that about 100,000 youth on the Autism spectrum turn 18 years old every year, transitioning officially into adulthood. The overall prevalence is estimated somewhere 1-2%. Okay. Young people with autism experience very high rates of co occurring medical and mental health conditions, including intellectual disability, as well as physical health challenges. Recent survey data also indicate that young people on the autism spectrum have elevated rates of socioeconomic disadvantage.

As an example, about 30% of children with autism are estimated to live in very low income households below the federal poverty level, compared with about 25% of children with other special healthcare needs, and 20% of children with no special healthcare needs, hence the elevated risk of socioeconomic disadvantage. Okay.

An additional challenge for young adults on the autism spectrum is the very nature of autism can mean multiple intersecting needs. Many of them will need various kinds of support from multiple providers across different systems of care. That can be increasingly difficult for them to access the care that they need, meet those complex service needs as they are transitioning from the child to adult service systems.

There's also for those of us who study of transition age youth, there's a commonly known services cliff that young adults can often experience as they leave high school and they complete secondary education because schools can be a crucial source of connection to different service systems and systems of care. As they leave school, they lose their connection to those access points. Okay.

Finally, as I'm going to be talking about it a little bit. There's not a lot of good data, and there's not a lot of there's not a lot of evidence and not a lot of high quality evidence to inform policy and practice to support the employment of this particular population. Hence, ODEP has funded this project to try to provide more data and better evidence. All right.

Next slide, please. So the project activities, we've conducted several different activities in these first three years of the project, including literature reviews, listening sessions, a data scan of the existing survey administrative data. We conducted a deep dive into post WIOA. Data from vocational rehabilitation agencies, and we also developed for evaluation design options for DOL to consider. Were they to fund evidence building activities to test some of the more promising programs that aim to support the employment of autistic young adults.

Of course, today, I have limited time. I could take 2 hours talking to you about all of our findings from these activities, but I am going to focus on just two of the exercises that we completed, and I'm going to be sharing some of our plans for an upcoming survey of autistic young adults. Next slide, please. Okay.

Next slide, please. All right. We conducted some listening sessions, as I mentioned earlier. The goal of these sessions was to collect input about barriers and facilitators to employment and career development for young adults on the autism spectrum from key groups that would have insight on these topics. We did this really early on in the project, and that's because we wanted to collect input from the community from autistic young adults themselves, from service providers really early on so that their perspectives could inform all of the subsequent planning and content of project activities that occurred after these listening sessions.

So we conducted a total of nine sessions. Each of them lasted 90 minutes. We tailored the topics of each discussion to the relevant perspective of that group. We started by conducting listening sessions with professionals who work with autistic young adults.

So this was about five sessions that focused on advocates, policymakers, direct service providers, educators, employers, and researchers. Those sessions were conducted between February and April of 2022, and in total about 48 individuals who reflected these professionals perspectives attended. We also recruited for listening sessions with young adults on the autism spectrum. These were conducted between March and April of 2022, about two years ago.

In total, we had nearly 100 autistic young adults, I think, exactly 97 who participated across the four sessions that were held. Naturally, these were voluntary sessions, we invited people to participate and we offered them compensation to thank them for their time. We recruited first from the networks of participants in those prior listening sessions of this professional groups, as I mentioned. And then for the next three listening sessions, we actually recruited broadly from the public using social media, e mail, newsletters, et cetera.

Okay. So participants in the young adult sessions could remain anonymous, I want to mention. We offered various channels for them to participate. They could turn on video, audio or chat during the session, and we also invited them to just share their perspectives by e mail outside of the session if that is what made them more comfortable.

Next slide, please. I want to start by just describing four direct quotes that we heard from participants that really infused their voice into these listening sessions and some of our findings from the listening sessions. One said, "I feel like I face additional challenges related to my position in my society. Because not everybody knows how to communicate with me and I cannot get what I need."

Another said, "I have worked with some programs that have really helped me gain courage while on the job market." "I enjoy working with others who are neurodivergent, because I would never be as confident or successful if it wasn't for older neurodivergent workers who took me under their wing and showed me it was possible." A fourth, "people with autism are also able to make good managers and leaders as long as you accept yourself, surround yourself with a good supportive system, and keep going towards your dreams."

Next slide, please. Okay. So I'm not going to spend too much time in the detailed findings from these listening sessions.

We have a report that synthesize what we learned, that's online. I can drop the link in the chat. But some high level findings can be shared here. This is synthesizing across both what we heard from the young adults themselves, as well as from the service providers and other professionals who have been working with this population or who have been involved in policy or research about young adults on the autism spectrum. Okay. So some of the barriers to employment that were highlighted were challenges in the job search process itself, and finding a good work environment that was a fit for them and their support needs.

Some pointed out biases in typical recruitment and interview processes that essentially would disadvantage someone who was near divergent potentially. Many talked about the need for greater and more enhanced supports and services. As an example, addressing their transportation needs or technology, providing ongoing supports while they're in the job, not just helping them get the job, but helping them remain on the job and thrive in the job and developing self advocacy and career advancement skills so that they could progress after they got that. Several also pointed out the challenges with generalizing and scaling services.

There are many programs that aim to support young people on the autism spectrum to get a job, but they tend to be smaller, more local programs and there are real challenges in figuring out how to scale them up to larger levels and to serve more youth. However, turning to some of the more bright spots that we heard, we also heard about a lot of facilitators to employment. Encouragement and advice from family members, friends, and the program staff was really key. Paid internships, career mentoring programs, customized employment options were pointed out as things that enabled success. Okay. Okay.

Some of our participants mentioned the need for cultural shifts, training for employers to encourage inclusive recruitment hiring and work environments. They mentioned that when they saw firms had implemented these practices, they were much more successful in hiring and retaining neurodivergent workers. More collaboration and funding for the needed supports that we mentioned, partnering with neurodivergent consultants, career coaches with disabilities, really experts who can help them navigate both getting a job and then thriving on the job, and then coordination with larger and more established programs as an opportunity for greater generalization and scaling of services.

Next slide, please. All right. The second exercise I would love to talk about is the inventory of existing survey and administrative data that we conducted. Essentially, ODEP asked us to do a scan of the landscape to identify what data already exists. We looked for data sources that met certain eligibility criteria. So it had to include young adults age of 16 to 28, It had to include enough information to identify individuals who are on the autism spectrum. And because this is an employment focused project, it had to include some employment related measures.

So as an example, a dataset entirely focused on health measures would not have been captured in this data scan. We identified 11 datasets altogether. Eight of them were survey sources, and we have three administrative datasets. We summarize them all in a brief. The link is on the slide, and I can drop it in the chat when I'm done presenting as well. Next slide, please. Okay. So I won't go through every data source one by one, but let me step back and reflect on some of the higher level findings from this exercise.

As I mentioned, we identified 11 data sources, which is quite promising in terms of the sheer number of datasets that are available. But I want to note some of the challenges that we identified when looking across these data sources. The first is that the identification of autism really varies across the data sources. Some of them might rely on medical documentation. Others might allow for self reports. Others might rely on, educational, sort of IEP data, et cetera.

And one of the reasons that this is a challenge is not only because it makes interpretation across the data sources difficult. But in the world of autism in particular, there's a lot of research that shows concerns with some of the ways in which autism has been identified and is being identified and disparities across different communities.

As an example, historically, we know that Black and Hispanic children were less likely to be identified than non Hispanic white children, and that there might be sort of non medical factors that played a role in those disparities. It might come down to sort of practices among healthcare providers, as well as some of the present the typical presentation of autism or what was thought to be typical for many years. So there's all kinds of structural systemic factors that could be biased and who shows up in these datasets because of the variation in identification mechanisms. There were some of our larger datasets tended to be from administrative sources, but those would focus on a specific population.

As an example, vocational rehab data, of course, we'll pick up NEDR clients who are on the autism spectrum. But this necessarily is a tiny fraction of all young adults on the autism spectrum and might not be representative of all of them.

As an example, as another example. There are files based on Social Security administration data on children who are receiving supplemental security income as an example. But SSI is a means tested benefit. There's all kinds of eligibility criteria to get SSI, and so that is probably not going to represent general characteristics of the population of autistic young adults.

Okay. We found that most contain pretty limited employment information. So at best, they contained kind of whether or not someone was employed and maybe some information on earnings, but they really didn't have detailed information about things like their type of job they had, occupation industry, the quality of that job, such as, you know, the access to fringe benefits as an example or potential for career development, and none of them contained information sort of from the participant's perspective about their satisfaction with the job, et cetera.

I also note that there were very few that were really dedicated to autism. That means that autistic young adults were part of these data sets, but a very small part. They weren't the full sample or even the majority of the sample. That means that once you drill down to the core sample of autistic young adults, that can mean pretty small sample sizes, which really inhibit rigorous statistical analyses.

So looking across these data sources, one of the takeaways was there's a need for more large sample, more representative data on young adults on the autism spectrum that is focused on employment information. Because without better data, we really can't even understand what are the exact needs of this population, what is the current employment rate, for example, which is really the starting point that we need to establish before we can think about how to develop better policy and practice to move the needle on any of those outcomes.

Next slide, please. So excitingly, that is a great segue and the third upcoming activity that I wanted to talk about. ODEP has funded a large survey of young adults on the autism spectrum, which we are currently in the planning and design stages of.

The goal of this survey is to create a large more rigorous data source on the topic of employment, and that is focused fully on this population of autistic young adults. The objective really mirrors the objective of the overall project, which is to provide insights into barriers and facilitators of employment for this population. Okay. We have several emphasis or guiding principles that we're using as we make all of our decisions around design. The first is to really try to make the data policy relevant. So we want to be able to answer questions that can quickly be used to take action on improving policy to support employment for this population.

Okay. Our second second sort of guiding principle is very intentional inclusion of historically under represented groups among people with autism. Historically in the data, partly because of some of those issues I mentioned earlier around disparities and the identification of autism.

Historically, females, racial and ethnic minorities and people who have very high support means on the autism spectrum have been left out of much of the data collection that has happened. And so we want to be really intentional about including them in the survey. We want to try to get broad geographic coverage and a large sample size, both to support rigorous analysis and to maximize the generalizability of these findings. So we don't want to conduct a very local survey or a state level survey that can't be used to advance a more national conversation and policymaking debate.

And to put it simply, we're trying to balance the goals of scientific rigor and community informed design. We want to approach this not just as scientific researchers, but really to involve the autism community at every step along the way of designing and conducting this large data collection effort. Next slide, please. One more side, please. Okay. So how do we go about doing that? How do we balance these dual goals of scientific rigor and community informed design?

Well, one of the things we're doing is recruiting through community partnerships. So we are partnering with four autism related organizations to recruit and sample potential respondents for this survey. We have identified four organizations as suitable for such a partnership. We identified these four after a sort of pretty long and intensive effort of speaking with a much larger group of organizations. We held detailed conversations with 15 autism or disability related organizations to try to understand what their interest was in participating in such a effort, and also trying to understand what their capacity was for helping with recruitment, sampling, and survey implementation.

When I mean capacity, I mean both their organizational capacity to help with such an effort, which is going to, it's going to take a long time and considerable resources. We wanted to make sure that they were kind of up for this challenge. But also more practically that they had the ability to sort of help us recruit and sample respondents, so that they had enough connections into the community and enough tools at their disposal. For example, a newsletter or, you know, a social media presence to be able to recruit and sample respondents for this survey. Next slide, please.

So our survey design is actually a two stage design. In the first stage, we have two autism advocacy organizations with a large national presence. They have pretty significant community reach, and they have very kindly agreed to advertise the REYAAS survey to their members. So they will send out these invitations. Those who are interested and complete a self screener as being eligible for the survey will then be able to go on and complete the survey online.

And when I say eligible, I just mean that they confirm that they are 16 to 28. We don't want someone who's too young or too old because that is the focus population of this survey. So they just need to self screen their age and they need to confirm that they are autistic. We are not requiring them to confirm that they have formal diagnosis. Certainly not requiring them to kind of provide any kind of documentation. So um this survey will include people who sort of self diagnose as autistic, and we'll be collecting information during the survey to understand what proportion have a formal first informal diagnosis.

So essentially stage one is a broad call for participants. In stage two, we are going to be taking a more systematic sampling effort. There are two organizations have databases that include autistic young adults, and we will be sampling potential respondents from those databases. And what I mean by that is that we will be using some of the information about database members that these organizations already have to identify a subset of people that we would like to send invitations to complete our survey.

Okay. So after assessing the stage one sample, we can we can intentionally sample the potential stage two respondents. And that's a very purposeful survey design because, in stage one, we're doing this very broad, you know, call for participants.

One of the concerns is that the people who respond to the call, you know, we have fairly little control over this apart from knowing who is on these member lists. It could be that I'm just throwing out numbers out here. It could be that 90% of people who respond to that call for invitations are white, right?

But we know that that is not reflective of that is likely not reflective of the true population of young adults on the autism spectrum. And so in stage two, we can kind of intentionally oversample non white and Hispanic members of the databases in order to try to obtain a more balanced sample at the end. Next slide, please. At a very high level, these are some of the topics that we're going to be collecting information about on the survey. We want to learn about their demographic, personal information, we want to understand how far they got in school, whether they're still engaged in school. Naturally, the real focus of the survey is employment and job characteristics.

So have they got a job now? Have they ever had a job since they graduated high school, learning more about what type of job it is, the quality of that job, and also their experience on that job, how they're enjoying it, how they perceive potential for career development, et cetera. As context, we want to understand their health and any co occurring conditions. And we also want to ask about their use of federal income support programs. Next slide, please. Okay. All right. So the target sample size is about 3,000 autistic young adults. That's what we're shooting for. It's going to be a web survey, so done entirely online. It is approximately 20 minutes.

The incentive we're offering is $40 for the 20 minute survey. As I mentioned, we're currently still in the design stage. So the survey is going to be in field and, you know, invites will be sent out in 2025. And the findings will be shared in 2026 through a report, a webinar, and other methods. So please do keep an eye out for that. Next slide. And with that, I will pause and welcome questions and just a quick shout out that the link on that screen is to the project website where you can read all about the other activities that I didn't have time to cover and all of our reports and dissemination. Thank you for having me.

**Andrew Houtenville:** Great. Thank you. So the Q&A, people are pretty quiet today. I'm going to ask you some questions. Let me stop sharing. Stop sharing. Stop sharing. There it is. Just so I can ask some questions. We can chat and here comes one. What are age groups are the survey participants you're shooting for?

**Ankita Patnaik:** We are hoping for people 16-28 years old.

**Andrew Houtenville:** Okay. One question that I have is, or, too many questions. One thing is to urge you to think about collecting re contact information and maybe encouraging ODEP to at least allow for the possibility of follow up because if you're going to get 3,000 youth and young adults on the autism spectrum, that's going to be a big effort, and it would be really a shame to lose contact. Okay. And so I would urge you to kind of push ODEP in that direction if you haven't done so already.

**Ankita Patnaik:** Yeah. Thanks Andrew. That's a great point. Yes. If we can get 3,000 people. It'll be a huge resource. I didn't mention this, but we are ourselves planning to recontact a very small subset of the participants to do actually one on one interviews a few months later. And that's the kind of dive into some of the thornier topics that are hard to cover by a survey and are just more qualitative in nature. But I think that's a great point. I don't think we can squeeze a follow up survey into our project timeline, but ODEP can always leave it open. In the future. Yeah.

**Andrew Houtenville:** Yeah. Will you be collecting data on participation, use of transition services through their school VR, et cetera?

**Ankita Patnaik:** So we're going to be collecting information about participation in job training programs. So VR accounts but also kind of DOL related programs, like, have you used an American Job Center and things like that. But I don't believe our current instrument is asking about school services.

**Andrew Houtenville:** Would you be, so ODEP funds the CPS supplement. And in that they've developed some questions and actually, I think Gina was a part of it as well in the most recent ones. You know, even though it's going to be a very different sample, just using as many variables from that. They they have service questions, and so I don't remember if it was transition services, but it might help you get a frame of reference to at least there's no good cognitive proxy. There's no good proxy for autism through the ACS six that the CPS uses. But are you able to let us know what agencies two groups you're using?

**Ankita Patnaik:** Not just yet.

**Andrew Houtenville:** Yeah. I figured. Okay. How are you distributing this survey? What regions of the US are you targeting?

**Ankita Patnaik:** Yeah. So as I mentioned, the first both I can say that all the organizations are sort of nationwide, so none of them are local or state specific works. So in the first stage, when they're advertising, I will technically go out to their sort of national member list. As I mentioned, there might be differences in, you know, who responds to that call for participants.

But it is open to the nation. And then we're going to look at the data from that first stage and see if it's, you know, hugely skewed. For example, if I don't know, I'm making this up, 60% of people are from New York State. Yeah. Then in stage two, we do have the data from the databases to be able to intentionally try to scatter the sampling more broadly across the country.

**Andrew Houtenville:** One thing to do, you know, and I thought a lot about how to try to upgrade the idea of using advocacy organizations to collect sample. And if they have any information and the one you just mentioned geographic location would be one potential variable by which you could look at invitation sent, if there's some way with some of the online survey structures, instead of having it be an e mail, to get the number of people who viewed it and didn't click through to it, you know, because that reticence, of course, the more information you have, a priori, through their membership database, the better. However, you know, things like if you could figure out if the parent is involved is also a member and the child is a member. Is it just the parent that's a member, that may signal some degree of severity, potentially, any kind of information you can get to see just who's viewing it and who clicks through. If there's a way to validate that they actually have seen it, not just sent it, but they've seen it and didn't click.

**Ankita Patnaik:** I really like that. Yeah.

**Andrew Houtenville:** Return receipt for e mail stinks. So if you got the idea that you know that the e mail was sent and it wasn't clicked through so that you get because you don't have a probability base. And the biggest thing, you know, but you try to get as close to it as you can, and that's where the first big decision is made after selection into the agency, it's you know, I just try to think really carefully about I don't know how you upgrade the use of a convenience kind of sample. And we've talked about this before with other things you're doing. Yeah. But

**Ankita Patnaik:** No. I really like that idea. Thank you, Andrew. Using the e mail metadata, right? Like how get rid of the bounce backs. Just look at the people who we know the e mail was delivered to and then if we can get an opening rates and click through rates as all part of sort of a response bias analysis.

**Andrew Houtenville:** Right. And if you can get metadata on time from receipt to Well, you can't there's some you can't just get. Like do they open the e mail? Do they just trash the e mail does, you know, from invitation to open, you know, that duration might give you some useful information. If you do a second don't let them share because then your frame is busted, you know? Like, if it's a shared one track whether they're shared well, we you know what to do.

**Ankita Patnaik:** You mean, like shared the invite?

**Andrew Houtenville:** Yeah.

Ankita Patnaik: Yes. So we will we have safeguards in place to make sure they can't just like forward it onto their friends and be like, Hey, here's a $40 survey. So we will have Everyone who got sent the e mail, we have that e mail list and you have to enter your e mail when you try to take the survey and so we cross check to make sure you were from that list?

Yeah. Yeah. Do you have, so this actually goes back to some work mathematica and others have done years ago around there's non verbal, verbal, and then there's independent typing and supported typing and those kinds of things and just proxy uses as a whole. Are you guys putting in anything to collect that information?

**Ankita Patnaik:** Yes. So I think yeah, two separate things. We are allowing proxies to take the survey and they'll have to self identify as proxies and tell us what the relationship to the young adult is. And then we do have questions about communication support needs. And that is one of the factors we might intentionally sample on for the second stage. So for example, if everyone in the first stage tells us they are verbal, then in the second stage, we have the databases have enough information for us to intentionally oversample those with high communication support needs.

**Andrew Houtenville:** Are you going to so you mentioned four organizations, but there's also expanding it to 15 others that you interviewed?

**Ankita Patnaik:** right now, the plan is just to do these four and see what kind of sample we can get from them. We chose these four because they, you know, they tick the boxes for the capacity to support recruitment, like others, for example, might not have had a mailing list or they might not have had enough data to support sampling, et cetera. So we'll revisit if we have to, but ideally we won't have to.

**Andrew Houtenville:** Yeah. Okay. Sounds great. We're up for time. Thank you Ankita for presenting. I look forward to seeing 3,000 observations and, you know, follow up surveys for ten, 15 years out, you know annual update, something like that.

**Ankita Patnaik:** Thank you very much for having me.

**Andrew Houtenville:** Sure. All right. Thank you, everybody. Thank you to our interpreters and to everybody at Kessler and AUCD. Bye bye everybody Have a good weekend. Okay.