

ROUGHLY EDITED COPY

AUCD-AIR-P January Webinar-(Zoom)
Association of University Centers on Disabilities (AUCD)

JANUARY 21, 2020

CART CAPTIONING PROVIDED BY:
ALTERNATIVE COMMUNICATION SERVICES, LLC

www.CaptionFamily.com

* * * * *

This is being provided in a rough-draft format. Communication Access Realtime Translation (CART) is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

* * * * *

>> Okay, the captions are here. So I'm going to hit record on my end just in case. But I will let people in now.

>> Hello, everyone. Welcome to the webinar series for autism intervention for research intervention the physical health, the AIR-P. I'm Kashia, and I want to thank all for joining us today. Before we begin, I like to address a few logistical details. I will provide a brief introduction for our speaker and reserve time to answer questions at the end of the presentation. Because of the number of participants, your audio will be muted throughout the call. However, you can submit questions at any point during the presentation via the chat box on your webinar consul. Entire webinar is recorded and will be available. Which is AIR-P. And there will be a short evaluation survey at the close of the webinar. We invite you to provide feedback and also provide suggestions for future webinars as this is the first of many monthly webinars hosted by the AIR-P. It is now my honor to introduce Jessica Rast. Jessica is a researcher at A.J. Drexel Autism Institute at Drexel University and author of recently published national autism indicator report on health and healthcare. Please join me in welcoming Jessica Rast. Jess yes thank you so much and thank you for being here.

>> JESSICA RAST: Thank you for being here and I'm looking forward to presenting our finding today. I'm going to talk today about health and healthcare and autistic children and adults.

I want to start first with a note of language. Throughout the presentation, I try to use the term autistic when talking about the people presented in this data today. I also sometimes use the term ASD or on the autism spectrum. I do try to show preference for the term autistic. And I apologize if and when I mess up on that. But I want to point everyone to this current commentary online language that was recently published in autism and adulthood. It does a great job of explaining why I'm paying attention to this and why I think other people should be as well. It explains the role of language, and how we communicate with people. And how language is connected to ableism or discrimination against people who are differently abled.

All right. So I'm going to start by telling you where I came from. I work in the life course outcomes research program at the A.J. Drexel Autism Institute. There we take up public health approach to autism. That means we aim to understand the experiences and prove the outcomes of people on a population level. We also take a life course science approach to our work. And in relation to health, what that means is health and healthcare changes across the life course. And experiences of health earlier in life have an influence on their later health outcomes. And a person maybe be more vulnerable to developing health conditions or experiences and disruptions in their healthcare at their critical points in their life, including the transition to adult healthcare.

Furthermore, health is influenced by complex mix of biological, social and societal factors and those also change across the life course.

So we like to use this visual metaphor to talk about the work that we do. This is a car dashboard, although there's not much dashboard to speak of here. This is an old Model T. So people drove these cars and had fun doing it but they didn't have any measure of how fast they were going or how much gas they had or how far they've come. Our currently understanding of autistic people, particularly adults is unlike the model of a dash model of Model T. And we have outcomes of autistic adults, but in the U.S., we spend billions of dollars to serve autistic people. And in a report from 2013 from the interagency autism committee, they showed that between 2008 and 2012, federal and private funders in the U.S. spend \$1.5 billion on autism research. And they're moving the needle on quality of life of autistic people.

And so enter a more modern dashboard into our metaphor. So I work at the life course outcome research program and attempt to provide national level indicators to understand how people are doing, what services they need or what they're using. What

factors are influencing how their lives turn out. And what current strategies are being used. And how they're working.

These are the types of questions that we focus on, because they're useful and practical. And they have the power to inform real world decision-making in government and service agencies.

We are aiming to build a dashboard like this of indicators across outcomes and across ages.

And so how do we do this? We're building these gauges using national data which helps us capitalize the money that's already been spent. We create information products that are accessible, understandable, and impactful. And we identify gaps and data between what is available and what we see as needed.

Okay. So now that I've shared a little bit about where I'm coming from, I'll share with you some findings from our most recent report. So these are related to health and healthcare. And this is part of our attempt, our outline going attempt to build these indicators. Particularly, around health and healthcare.

And how things are turning across the life course. Health and healthcare.

So why focus on health? We focus on health here, because health is an integral quality of life. When you have good health, you may not be thinking much about it. But when your health is poor, it impacts all aspects of your life.

So then why focus on healthcare? Health and healthcare are very intricately related.

And very much in the same way, health insurance and policy impact healthcare. And reimburse patterns are not optimized for comprehensive healthcare. And there's been a recent national push to focus on health in autistic people. So good example is this HRSA re-investment in the AIR-P research network which is the venue which we're presenting the findings today. The autism CARES Act 2019 requires a report be submitted to the Congress on the health and well-being of autistic people. The interagency autism coordinating committee which is part of the U.S. Department of Health and human services can be a subcommittee to address the health needs of autistic people. And there's been a surge in national research attention on health starting to identify this as an important issue.

So, need for this report also comes from the knowledge that autistic people often have trouble access, the care they need. So we know they often have complex health needs. They may use care more often and how healthcare cost than their peers. And they may have more emergency department visits and in-patient hospitalizations. And

then even when they do access healthcare, we see higher reports of unmet healthcare needs. And then there's a few contextual points I want to make. Social and political factors influence health and health services. Access to things like healthcare policies. And also includes race and ethnicity which influences health and healthcare. Healthcare needs and health change across the life board. And early experiences in health and healthcare impact throughout the life course.

And then, certain parts of healthcare are more complex than others. And we know one of those points is the changes between pediatric and adult healthcare.

So with all this in mind, the purpose of this report is to catalog health and healthcare and autistic people across the lifespan. Highlight the inadequacies in current care systems. Support recommendations for improvements in health and healthcare. So then we will cover the following topics to this end.

We have 5 chapters of results. I'm going to go over those. And we have overall health. Health services. Medication. Insurance. Accessing services.

All right. And then after I go over those, I want to spend some time highlighting finding that expand on top of these areas and they deserve explanations. One of them is healthcare transition. Primary care gaps and racial and ethnic disparities. All right.

And then I also briefly want to mention we see these four sources of data for this report. And each represent a different population. So it's important to note what they are.

So the first two are national surveys conducted by the U.S. government. And they captured the health and healthcare of national sample of children. The third one is a sample of in-patient hospitalization in the U.S. from the year 2017. So this captures almost all hospitalizations excludes long-term rehabilitation facilities.

And last one, we compiled publishings from Kaiser Permanente in Northern California. Kaiser is a healthcare system that covers four million people in the greater Northern California. We included this, because there's a limited amount of national level on adults and what their health is like and what their healthcare system is like. So we decided to include this, so we start to see a picture, also noting that we have a gap here.

And Lisa Croen is a co-author on this report and co-author in many of the papers we pull for this report and leading investigator out of Kaiser.

Okay. And then throughout my presentation, I'm going to make explanations to a few groups. One of the main comparisons we make is to children with special healthcare needs and children without special healthcare needs. And in this context,

children with special healthcare needs are defined as children who use more services than other children their age would be expected to use. And for conditions that are expected to last longer than 12 months.

This designation is not specific to conditions, but most children who have qualified for being a child with special healthcare needs also have a health or behavioral health condition. So, for example, from the surveys that we used, nearly all autistic children also meet the definition of being a child with special healthcare needs.

All right. And then a warning before I start. I just want to let you know these slides will be available after the presentation. I want to take time to mention this, because I'm going to be presenting a lot of data and a lot of graphs on the following slides. And you may find yourself desiring to look at them in a little bit more detail or a little bit longer. But I will do my best to point out what I think are the most salient finding and, hopefully, that will make sense. So we're going to start with the overall health.

So we'll start with an easy one. About two-third of parents of autistic children ages 3 to 17 rated their child's health is good or excellent. And we compared this to children with special healthcare needs and found a similar rating. However, children, parents of children with no special healthcare needs rated their child's health as much better.

So, then we asked, when they were asked about oral health, we see a bit of a different picture meant just over half of patients of autistic children reported their child's teeth was in good or excellent condition. And oral health appeared worse in autistic children than it did in other children. Where nearly 80% of parents of children with no special healthcare needs reported their child had excellent or very good oral health.

When we look more at the impact of a child's condition, we see that one third of parents of autistic children reported that the child healthcare conditions are problem usually or always impacted their ability to do thing other children their age can do. So this is in stark comparison to children with special healthcare needs where almost half report their child doesn't have a health condition or it never impacts them. And I just want to remind you that special healthcare need is related to the amount of healthcare that a child uses or needs. And may or may not be related to a health or behavioral condition.

And another dimension of health is presentation of co-occurring conditions. So here we're examining the most prevalent co-occurring condition in children. When parents were asked about whether their child had certain health conditions, autistic children are rate of autistic children had rates of asthma.

So the common conditions were learning disability, developmental delay. And then we can also see half of children have behavioral or conduct problems or speech and language disorder.

And certain conditions varied in prevalence by rates of autism in children.

And they were most common in white non-Hispanic children. As developmental delay, which is in opposite corner, the upper left and bottom right are the most common in Black non-Hispanic children. And two graphs in the middle, learning disabilities and speech or language disorders are more common in Black and Hispanic children than they are in other children.

There were also able to look at co-occurring conditions and transition age youth and study that's defined from ages 15 to 25. And this is one of those Kaiser Permanente previously published finding. And this particular study found that most psychiatric conditions were more common in autistic transition age than their youths. Including anxiety and bipolar and medical conditions were more common in autistic youth. The exception is third from the top up there, musculoskeletal condition. Now we can take a look at co-occurring conditions in adults. This work about Croen by Kaiser records. Age 18 and over. So we see the same pattern in the transition age youth. And this is more common in autistic adults than peers without autism.

The most common conditions at the top railroad stomach and intestinal disease and oh obese and anxiety. And I want to point out higher rates of hypertension which is a potential marker for physical healthcare and then epilepsy, which is much higher rate than normal.

On to health services. Understanding how people interact with their healthcare and how their healthcare system provides for them can help us improve outcomes.

So we'll start with parent report of healthcare visits. 95% of children had a visit with the medical provider in the past year. That was similar to children with special healthcare needs. But more than children with no special needs, which reported 70%.

Notable finding is that autistic children went to the doctor a lot more. So the average number of visits to healthcare provider was 29 for autistic children compared to 9 for children with special healthcare needs.

Although visits to healthcare providers were common, they were less common in Hispanic children. And we found only 80% of Hispanic children had reported visiting a healthcare provider in the past year.

So visit to doctor is not the only or maybe the best marker of healthcare. We can also look at qualities of care to see what differences might exist there. Here we're

looking at the presence of a usual source of care and the presence of a doctor or nurse. Usual source of care is someone of the parent reports the health need and nurse or doctor knows the child and knows the health history when he will. And the non-white children were to usual healthcare and along with children of multiple races who were not Hispanic.

And special care is another important consideration. And here we're looking at mental healthcare. Nearly half of autistic children receive treatment or counseling from a mental health professional in the past year and that was a percentage larger than children with special healthcare needs and children with no special healthcare needs. And this varies by age. So just over half of older children ages 12 to 17 received mental health care versus a third of younger children receiving healthcare. And we know this is different by race and ethnicity where the Hispanic children are least likely to receive this type of care. About a third reported compared to about 50% of all other children.

So another aspect of healthcare is expenditures. Both out of pocket and insurance expenditures. The average total expenditure for all healthcare in the past year was highest in the group of autistic children. It was \$13,000 per year. Out-of-pocket expenditure which is expenditure the family pays themselves so that might include copays. They were also higher in the autistic group than other children.

So the way we interact with healthcare system changes over the life course. And possibly one of the biggest changes is when we change from pediatric to adult care. This process is formally known as healthcare transition. And reports of transition services and children with autism are very low.

So taken together, all the components of this graph make up the transition process. Some of the components are more often met like the top we see that three-quarter of autistic children work with their providers to make positive health choices. But others are very rarely met. Down at the bottom, we see fewer than a third. And as little as quarter of children work with their provider to understand the changes that happen at age 18. Create a written plan to transition their health. And discuss the switch to an adult provider.

I also want to point out this highlighted, the second from the top bar. So the provider working with the child to gain health skills. 20% children with autism report this and children with special healthcare needs. And I think that's really interesting finding, because we've seen so far that children, autistic children have pretty intense healthcare needs in comparison to this group. So if anybody is going to need assistance to gain skills to advocate for their health, it's going to be autistic children.

We also get a unique look at preventative health services. This comes from a Kaiser study from 0 to adult. So they were able to look at prevent tough services

receiving through their healthcare provider. If they found that autistic adults are more likely to get services including flu vaccine, closely and diabetes screening than their peers. We saw a little bit earlier that autistic children see the doctor more often. So it's possible this is part of a similar finding.

However, when we looked down at the bottom preventative services in women, we see this lower rate of cervical cancer screening in autistic women than their peers. This is problematic, as autistic women are very understudied population. And specific information and attention paid to the services they receive and how they interact with health systems is certainly warranted.

All right. Now we turn to in-patient hospitalization. We looked at autistic children and adults. And here we see both of these graphs share the average length of stay and average cost per day of inpatient stays. On the left, we're looking at children. So the length of stay was shorter in autistic children than it was in a comparison group of children with other mental disabilities. MBND stands for mental health and disabilities. And their stay was shorter and it was higher by \$4,000. And on the other side, we see the option. It was two days and cost was lower by a \$1,000. And this might have to do with the types of conditions that children versus adults are admitted for. And here are those conditions. On the left again, we have children and on the right are adults. So these graphs show the most common condition the autistic children and adults are treated for. This is the primarily condition. And ostensibly this is the reason for their stay. So for both groups, new disorders were the most common. However, we see differences between these groups. And children, epilepsy is much more common than it is in adults. And in adults, we see injuries. And schizophrenia and Septicemia are much more common.

So in both children and adults, many of these conditions are referred to as ambulatory sense condition. This is the idea that these are conditions that should not lead somebody to hospitalization if their condition is being adequately treated in primary care. But the high rates of these conditions is likely to marker, especially in children, they're not receiving comprehensive care for all of their conditions within their primary care setting. So next we're going to look at medications. So prescription use is common in children, autistic children and other children with special care needs. Three quarters of the children with autistic needs filled the spring in the past year. Here's the most common classes of medication. So the most common was central nervous system stimulants, CNS stimulants. Followed by antimicrobials and antidepressants. And so CNS stimulants are used in conditions like ADHD and such things as amphetamine, and ant microbial is antibiotic and anti-fungal. Only medication that was more common in children were special healthcare needs than autistic children is medications for respiratory or allergy.

I will point out that asthma is a very common condition in children with special healthcare needs. And that could help explain that finding.

So, some medications were more common in older autistic children than younger ones. This is true for medications that parents reported were used for autism. That was the worrying of the survey question. And one third of children ages 12 to 17 were taking medication for this purpose. Compared to 22% of younger children. And then we also saw differences by race and this type of medication use. So on the right, we see that white and Black autistic children were more likely to use medication for autism than were other children.

We see similar picture here for medication that was taken for difficulties with emotion, concentration, and behavior.

So half of older children ages 12 to 17 with autism took medication for difficulties with emotion, concentration, and behavior. And 30% of younger children did. And we see a somewhat similar pattern by race and ethnicity with nearly half of autistic children taking medication for this purpose. While only a quarter of Hispanic children were doing the same.

So we see some differences in medication use. And we can also look at medication expenditures. So autistic children had an average yearly expenditure with \$2,740. And again, out-of-pocket expenditures, the expenses that family pays them and including copays.

I also have a little data to share about adults. This is another Kaiser study that's by Zerbol, et well. And 08% of adults with autism, they were looking at ages 18 and older had one prescription a year. And they found very similar to adults with ADHD, and general population where 62% had a prescription filled.

So the most common medication are listed here. They were psychotherapy tick agents. Anti-infectives and medications for respiratory or allergy needs.

Psychotherapeutic was more common in autistic adults than other groups. And the bottom half of this group was smaller but adults were least likely to have it filled and were most likely to have filled cardiovascular medication. This particular finding matches the finding that autistic adults have higher rates of hypertension than their peers.

So our next topic is insurance. For many people, insurance is the Gateway to healthcare. And it also dictates what type of care we can receive and from whom. It's also an important place for intervention, because policies can dictate many insurance decisions. So most children had insurance at the time of the survey. And almost all

were continuously insured over the past 12 months. But we found public insurance was more common in autistic children than other children. Over half, 56% of children had either Medicaid or some type of public insurance. And we also found that younger children were more likely to have public insurance than older autistic children.

So, while nearly all children were covered by insurance, not reported all adequate insurance coverage. Only half of parents with autistic children covered the services they needed and that's the graph on the left here. And in the middle, about two-third reported their child could always see the providers they needed. But on the right, we see that only 44% reported that their insurance covered mental and behavioral needs.

Mental and behavioral health needs were largely a problem for all children, but these other areas of access to care seemed worse for autistic children than for their peers.

So insurance makes plans accessible but plans vary. One third of autistic children reported paying for the child healthcare during the 12 months. And one-fifth of parents avoided changing jobs because they had concerns of losing their health insurance for their child.

And these problems, again, seemed more common in families with autistic children than families of other children.

We can also look at the primary payer for the population. On the left, we're looking at children and on the right, as adults again. And so, in children, we see that about half had a primary expected payer of Medicaid. And that's very similar to children with other mental disabilities. On the right, when we look at adults, we see that two-third of adults had primarily executive payer of public health insurance. Largely similar to their peers with mental disabilities, although the portion who reported MediCare was smaller for autistic adults than the peers.

And then finally I have some findings related to accessing services. So this includes components of care and care models that improve care quality by care coordination and referrals. And also the medical home. And when I'm also going to discuss some unmet healthcare needs as reported. All right. So, as we've seen so far, autistic children use a lot of services. Integration of these services makes healthcare easier and it also makes it safer. One way to connect services is through care coordination. On the left, we see the parents whose autistic children used more than one healthcare service in the past 12 months. 28% reported they had help coordinated care between the providers. This is a very similar rate to other children with special healthcare needs. But larger than children with no special healthcare needs. And this

difference might be due to care complexity and the relationships families have developed with providers because of ongoing service needs.

On the right, we see that of these same parents, those who saw more than one provider, nearly a third of autistic parents, parents of autistic children reported they needed more help in coordinating their care, which was double the rate of children with special healthcare needs.

Again, the need for coordinating care varied by race and ethnicity by many more parents of Black autistic children reporting they needed help coordinating that care.

And many parents spent a chunk of change coordinating care for their child. So more than 1 in 4 parents spend at least one hour coordinating care weekly. While you can see on the bottom two rows, majority of parents with children of special healthcare needs and children with no special healthcare needs reported their child did not need weekly care. So the care burden is much different here.

And then the referrals are ways for providers may provide for the child to see. And sometimes it's a requirement by insurance plans for reimbursement and specialty services.

So of children who reported a need for referral, 40% of parents reported a need for referral. And we see a similar story for care coordination of those that were seeing providers, multiple providers, a third reported that they had problems getting the referrals they needed. And, again, this was higher rate than children with special healthcare needs and children with no special healthcare needs.

And then another concept that we investigated here is the patient center medical home. This is a model that aims comprehensive coordinated care with overall goal of reducing complexity. And it's differently at play and improving healthcare quality. So the medical home coordinate across multiple services and systems that provide care. But only a third of autistic children receive care within the medical home. Much fewer than children with special healthcare needs. And the 50% of children with no special healthcare needs receive care this way.

There's also variation by race and ethnicity. And only about a fifth of Black children are receiving care through medical home.

So with this reporting need for the low, or high needs for coordination and referrals and low use of medical home, it's probably unsurprising that parents are frustrated in services. More than half of parents with autistic children reported they were frustrated. And this frustration was more common in parents of autistic children than parents of children with special healthcare needs or no special healthcare needs.

Further, parents of younger children were more likely to report frustration than parents of older children. It's possible to navigate all this complex health landscapes and they haven't looked at the resources yet to deal with navigating all that.

And another dimension of service is unmet need for services. So, 11% of parents with autistic children reported their child did not receive some of the care they needed in the past 12 months. Of those parents, the most common reported unmet need was mental health services and half of parents reported that as an unmet need. Dental care was also very commonly reported unmet need. And that particular need span across all these comparison groups and children with special healthcare needs and children with no special healthcare needs also reported a high need for dental healthcare.

When we examined the reasons why children had unmet needs, the most common reasons were difficulty getting appointments. And issues related to cost. And parents, 50% of parents reported both of those as barriers to care.

So not only are there structural barriers of care, but there's personal and personnel. And this is a study by Zerbo, et al. to treat autistic adult patients. And three-quarters of providers rated their knowledge and skills for providing care to autistic patients as poor or fair. They also noted lack of support for the provider and the patient to receive adequate care. So the top two lines of this graph show that only one quarter reported that their patients or their patient's caregiver had enough support to partner with providers. And even fewer in the third bar reported that they had adequate tools to accommodate autistic patients in their own practices.

So I want to revisit some of these findings and highlight a few things that overlap across these different topics. So healthcare transition. I discussed the low rates of preparation for the switch from pediatric to adult care. Care is fundamentally different in childhood than adulthood as the responsibility for care falls upon the patient and not the provider or the parent once they're in adult care model. Transition often also includes changes to providers to treat adults and maybe a host of new specialty providers. But we saw few of them and third of autistic youth work with their provider to understand these changes, create a written plan for transition, or discuss the transition to different provider.

But that doesn't capture the whole picture, because who do these children transition to? I just shared these results couple of slides ago on Lo provider knowledge and inadequate support for autistic patients. And this is a common cited problem and the solution is very complicated. So none of the physicians in this particular survey receive formal training and screening or diagnosis for autism. And, again, 77% rated their knowledge and skills for providing care as poor or fair. And this is even worse in

some of the disciplines that they looked at. So 88% of OB/GYN reported it was fair. And we saw low rates of preventative services for autistic women.

All right. So I'm also going to highlight a few gaps in primary care. We saw little evidence it's unmet in comprehensive manner and we saw unmet needs for mental health services. Cervical cancer screening for women. And we saw the emergency department use and hospitalization where not different, the rates were not different between autistic and non-autistic people. But we did see the most common reasons for hospitalization in autistic children and adults were conditions that could be managed in primary care. Things that on that should not land in hospital. Mood disorders, epilepsy, and asthma are some of those.

So I also need to highlight the racial and ethnic disparities that persisted all 5 chapters of this report. ADHD and anxiety were more common in white non-Hispanic children than any other race. While asthma and developmental delay were most common in Black and non-Hispanic children. Racial and ethnic minority autistic youth are often misdiagnosed than white youth. And this may be misinterpreted. And we saw Black and Hispanic children were least comprehensive care and report of usually support of care.

And then we saw that half of families of Black autistic children had trouble paying for their medical care compared to the third of the other families. And Black children reported they need more help coordinating care and accessing referrals.

All right. So I reviewed a lot of results and I just wanted to summarize them. First, health services and intervention can positively influence health just as lack of these can lead to poor health. So we highlighted the need for improved healthcare and healthcare for autistic people of all ages. We highlighted racial and ethnic disparities related to health. And autistic people receive more services and spend more on healthcare and take more medication than their peers. We also saw complex healthcare needs and these make comprehensive care more important and more difficult for autistic people.

Barriers to this type of care can cause worse health. As we saw compared to peers. And providing more appropriate care and reducing these barriers can lead to better health and can lead to less usage of emergency healthcare and in-patient hospitalizations.

So, as always, this work highlights areas for future inquiry and need for attention. With this in mind, I end with a few recommendations for research moving forward. In general, more work is needed to understand why health and healthcare are worse for people on the spectrum. And determine how to improve these services.

With the overall goal always of improving health and quality of life. So, first, I want to say that we need to embrace this idea that all types of health are important. So not just physical health, but dental care, vision care, specialty care, and mental health care as was repeatedly pointed out in our findings.

These are all important considerations in health. And they all impact life and quality of life.

And having only physical health and health conditions is not enough, especially in autistic people where we saw high rates of medication use to the point of need for behavioral supports. And systems that support the provisions of this type of service. Lack of transition services was also especially problematic given the lifelong nature of the autism and the experiences early in life impact outcomes later in life.

So second, we need to focus more on coordinated care to improve health. Healthcare is complex. Take, for example, in Chapter 1, I showed you reports of poor dental health. Reasons for poor dental health could be influenced by many factors. Lack of insurance coverage, need for behavioral supports, for successful office visits and for daily dental hygiene, dietary issues related to dental health or lack of accommodations at the dental office. So if these all impact dental health, a truly comprehensive approach to healthcare should support all of these in provision.

So third, we have to do a better job of addressing the persistent racial and ethnic disparities that pop up over and over. Acknowledging these disparities is the first step to addressing them. We need to do much more work to reduce them. Another area here that is applicable is the reliance of health insurance as, especially, prevalent for underserved and other represented groups. Research in this system can be emphasis for improving outcomes.

So fourth, assessing the impact of our current pandemic on autistic people. So I think the pandemic highlights the shortcoming and provision of healthcare to high-risk and hard to serve populations including autistic people. Inability to receive services timely and accessibly impacts care and exacerbates health conditions. And more involvement with the medical system also increases the risk of exposure to COVID. Right now, we have a unique opportunity to examine the impact of this system wide disruption on such a high-risk population.

And then I would finally like to end by saying that we need more data. While this report examines outcomes for multiple data sources and across the life course, there is an obvious emphasis on child health. This is not by desire. But by demand. And so comprehensive data on adult health and healthcare is largely unavailable at the national level. The data that we do have and we have presented comes from specific healthcare

systems or segments. And as a result, we don't have adequate information on nationally representative data to explore the needs and outcomes of adults.

I would like to acknowledge and thank profusely my co-author on this report. Andrew Roux, Christy Anderson and Lisa Croen, Alice Kuo, and Lindsay Shea, and Paul from math children and adults.

And I would also like to acknowledge contributors. So Andrea Abanto who did the graphic report. And Paul Cirillo who supported editing. And I also like to announce my funding acknowledgements. And is this project was supported by Health Resources and Services Administration. And we're also grateful for new funding from the AIR-P, Autism Intervention Research on physical health. And this funding will help propel our finding from ATRP forward. And this is a new resource for us and we'll still developing the project core work in this area, and working with the health services and systems within AIR-P.

And the full report is available online for those of you interested at our website, which is Drexel.edu/autismoutcomes/NAIRhealth. And you can scan this to take you directly there. Thank you.

>> Wow. Thank you very much for the presentation, Jessica. And also for your work in this area. So we now have time for questions and answers. I'll start with some of the questions that were already submitted in the chat. And I can read them out loud. But please feel free type additional questions in the chat box and I'll also read those for Jessica, the presenter as well. And I'll post a link for the feedback survey in the chat also. So I will start Jessica with the question from Peggy. They're asking if anyone knows the status of the IACC and will there be a concerted notice of soliciting family members and autistic persons both youth and adults, including more racial and ethnic diversity of the council? And how this council will better support policy for the life course of those with autism?

>> JESSICA RAST: Yeah, that's a great question. I think that's a question that keeps coming up. It seems to be popping up. IACC has been a bit quiet. I have heard they are definitely still working on convening their next membership council for the next session. They were refunded.

I don't know, I don't personally know anything about the status, except to know they are reconvening. I know that they continue to increase the presence of self-advocates and family members on their board, which I think is a priority of theirs. I do not know anything about their priorities as it relates to racial and ethnic diversity. But I hope to see that as a priority for them as well. And also gender diversity. We also had couple of comments from Dana, who is actually one of our ARRB board, autistic researcher review board which has been insanely helpful with the AIR-P. So they were

asking some questions about interoceptive issues, reporting that's difficult. So they were saying they think it would not be a stretch who doc knows any way to know struggling to report. Like verbal or nonspeaking. And there also was a comment from Dana autistic women are massively understudied because they're often not believed or under diagnosed and this leads to trauma with the OB/GYN care and they begin avoiding it.

>> JESSICA RAST: Yeah, that's hey great comment. I agreed that's an understudied area and there's probably a lot of intricacies to why that's true and why women may not be seeking the care they should be seeking. Especially, in regards to preventative care and emerging health conditions. I really know very little about that area. And I don't know that I'm the only one that, researcher only know that knows very little unfortunately. But I really do think it's an important area of inquiry. And I would not be surprised to hear that researchers of AIR-P is looking into that.

>> Exactly. You're very correct. We have gender sexuality and reproductive health which is Lisa Croen on the NNIR. Definitely.

>> JESSICA RAST: I think the first point was about reason that people, parents may go to a healthcare provider to help understand their child. I really don't have much introspection on that point. But I think it's an important point. The way that a parent interacts with their child and the way the parent and the child have an opportunity to interact with the providers is important. Increasingly, it's seen as important the child has an opportunity to interact with the provider on their own without the presence of a parent to help build healthcare skills and be able to talk about sensitive topics as well. I unfortunately think that's probably going to be something that happens less with autistic children than with other children, just because provider relationships with children may be different for autistic children based on communication impairments or something related. And I think that's an important thing that needs to be overcome. Because it's an important aspect of healthcare, as we talked about today, it's a necessary thing for all people, not just people who their doctor can communicate with.

>> Okay. Thank you for your feedback on that. Jill is asking if there are higher rates of hypertension in autistic adults. I'm sorry, are the higher rates of autistic adults controlled for obesity?

>> JESSICA RAST: I don't flow the answer to that question off the top of my head. So that was a Kaiser study. We did control for many factors. And I would not be surprised if obesity was one of the factors. We did see high rates of obesity in autistic in that same graph. But I don't know for sure. Because citations for those papers are available in the report. But I can probably, I can also share those too if you want to add them to the website when you post the slides.

>> Perfect. Thank you very much. There were couple of newer questions. Let's see. Have you found any data on autistic persons who also identify as transgender accessing healthcare?

>> JESSICA RAST: No. So as I've mentioned, there's really limited data on autistic adults. I think that the compounding issue here is intersectionality between autism and gender identity, which is also an understudied area. And in general, but also in medical health. There could be studies that address this. I know there's no national level data that addresses this, which is generally the type of data we use to present these findings. I also wouldn't be surprised if that was an area of inquiry for one of the AIR-P notes because it could fit in with that. But I don't know any research into that.

>> Yep, it definitely fits within the gender sexuality and reproductive health note. And these are anonymous attendees asked two great questions. They're asking what is a medical home? And what is an effective coordinate care practically look like?

>> JESSICA RAST: That's a great question. Medical home is a concept of providing care that makes the more comprehensive. So it's not a physical place. It's a same physical place the child may go to, but the provider coordinators with the other provider on the child's care and needs. And there's a centralized medical record so the records of the child's visits across the providers are available for all providers. And there's care family center, so the provider includes the family about the additions on care and listens to the voice of what they want to do with the child's care. What does care coordination look like in practice is a complicated question.

So integrated care, there's level of care integration and the lowest level is care coordination. That just means you have separate providers that decide to communicate with each other about your care. This is, the reason why it's complicated, because it takes time to coordinate care. So your provider has to take time or somebody at your provider's office to speak to another provider that may or may not be an activity that's reimbursed by your insurance. So they may not be able to bill for their time of coordinating your care. So there are barriers for care coordination, but there are providers that coordinate care in that way. But coordinating care just allows all your providers to know what's going on. So you get better care. You have to repeat yourself less and you have more safety in your care, because you know, maybe you have an allergy that's a medical allergy that one of your providers know about. But if they didn't tell the other provider, there could be no overlap in that knowledge. That's just one example. But it's a good idea. But it's hard in practice.

>> And we'll likely hear more about care coordination and the medical home model in future AIR-P webinars. We're running short on time. There were two other

questions. One was asking about any stats on employment losses for the mother of autistic children? And we also put the link to the full publication into the chat. I know you also chaired it on the slides as well. And then also there is a question about are there models of best practice for transition to adult healthcare?

>> JESSICA RAST: I'll start with the last one. So there are models of care for transition. There are national and state Governing Body that say how transition care looks. And practices can choose to do it in an individualized manner but they tonight have to nor should they. There's bodies out there that tell providers the best way to provide this type of care. So there is some oversight is not the right word, but suggestion how this should happen.

I don't remember the first question.

>> No worries. You have gone through quite a few of them. 12 in total. It was asking about statistics related to employment loss for mothers. But, thankfully, we've been able to provide the link to the report. So there might be some more information in there. Because it looks like we're at time. So I put a link in the chat to the survey for attendees to please fill out and provide us some feedback. Buffet I want to take the very last-minute to thank everyone for attending the webinar and thank Jessica very, very much for taking the time to provide us more information about the national autism indicators report. It's been very interesting hearing about it. As I've said, the webinar will be recorded and will be archived on the AIR-P website. Please take a moment to fill our survey and thank you, all, very much for attending. Thank you, Jessica. Have a good rest of your day.