U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 6 – Question 6 – What does the Future Hold, Particularly for Adults?

Conference Call 2

MONDAY, OCTOBER 3, 2016

12:00p.m.

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PROCEEDINGS:

DR. SUSAN DANIELS: Thank you. Hi, this is Susan Daniels from the Office of Autism Research Coordination at the National Institute of Mental Health where we manage the inner agency autism coordinating committee and I'd like to welcome you to this conference call Number 2 of the IACC Strategic Plan Update Working Group for Question 6 on the topic of what does the future hold particularly for adults.

I'd like to welcome our public audience listening on the phone as well as our chairs - Mr. Brian Parnell and Dr. Julie Taylor who are both members of the IACC as well as all of the members of the working group and thank you for volunteering your time to help us with this task.

So, on our previous conference call we talked about the research that has been done in the past and the portfolio analysis that my office did to try to understand what is happening in terms of funding. Today we're going to be talking about advances that have been made in both research and services and policy in the area that relates to adults and adolescence on the autism spectrum.

So from the previous call I don’t believe there was any outstanding business that we needed to follow-up on. I did follow-up on some information about additional groups for future reference for the portfolio analysis and we'll consider what we might be able to do with that.

So for today's call we're going to be starting with a discussion of public comments received through the request for public comment that the IACC put out over the summer and so this request for public comment requested that the public provide comments on all of the seven areas of the strategic plan and their concerns, ideas for these areas and we collected the information we received 1100 comments overall.

And I've provided you with a list of the themes that our team here in the office found within the comments and the themes that are listed here, access to quality adult services, adult diagnosis, community inclusion and integration, housing, transition, long-term financial planning, assistance navigating the service system, qualified workforce, quality of life, health and safety across the lifespan, vocational training employment and post-secondary education, choice and autistic perspective.

Some comments that endorse the current policy or the current priorities that were already in the strategic plan and some comments that suggested that the focus should be on early intervention rather than on adult services and lifespan, but you know, there are a variety of different types of opinions that were shared throughout this request for public comment.

And so if you've had a chance to look through this list of themes or browse the actual comments which are found on the IACC Web site by a link that you can get to from the carousel of images when you first get onto the Web site or through the meetings tab and at the bottom there's a public comment tab and you can navigate through that to get to the actual public comments.

Do members of the committee or the working group have any comments about what you saw in the public comment?

MR. BRIAN PARNELL: I have one Susan, this is Brian.

DR. DANIELS: Hi.

MR. PARNELL: I wondered if we should add an additional category and call it support for caregivers or if the group thinks that that might be subsumed under the choice and autistic perspectives. I just heard a lot of desperation, caregivers, parents’ of people with autism crying out for help and I want to make sure that we capture those thoughts.

DR. JULIE TAYLOR: Hi Brian…

DR. DANIELS: that was an important theme that was in the public comment and I think it would be fine to add that to the list of themes.

DR. TAYLOR: This is Julie Taylor I had the exact same suggestion Brian so we're on the same page on this. Just because people with autism are adults and we want to focus on their own needs, caregivers are still doing care giving and in some cases very intense care giving. So, we need to make sure that research around their needs and how to betters support them is also a piece of this, I think.

MS. AMY GOODMAN: Yes, this is Amy and what I think is what happens after the caregivers can no longer take care of the person, what happens to the person or the individual on the spectrum?

DR. DANIELS: That's another important topic.

DR. NANCY CHEAK-ZAMORA: This is Nancy, I think that goes within the caregivers comments as well. I at least hear them say that a lot like that's one of their major concerns.

MS. SAMANTHA CRANE: I would add - this is Sam Crane, I would add that, you know, the thing that we don’t see in the comments that is still very important is aging of the autistic individuals themselves. So that's combined with what happens when the caregivers age, because these things happen at the same time but we have people on the spectrum who are 70 years old, 60 years old and they might have very different needs than 20 or 30 year olds or 35 or 40.

DR. LAURA KLINGER: And this is Laura Klinger, I had the same thought. I'm not sure if this is well represented in the public comments that I was going to suggest that that's an area that we address.

MS. CRANE: I think one of the reasons why we might see it represented in the comments is because we're getting a lot comments from caregivers but there aren't that many people who are around who are still caregivers of 60-year-old autistic individuals. So they might not have a voice represented in this comment.

MS. GOODMAN: That's true.

DR. SOMER BISHOP: This is Somer Bishop, another thing that I think wasn't reflected as much as it could be in the public comment is thinking about quality of life, not just as being tied to physical health but as being - you know, as having components of emotional wellbeing and happiness and so just making sure that we have that adequately represented in the goals; how are we going to make sure that people lead happy and meaningful fulfilling lives as they would define.

MS. GOODMAN: Umhmm.

DR. EDLYN PEÑA: This is Edlyn - I'd like to echo that. I think that tying it to mental health is really important since there are a lot of co-occurring conditions with anxiety and other mental health issues, I think that’s important for adults.

MS. CRANE: And suicide as well. Sorry, that's Sam.

DR. PEÑA: Yes.

DR. DANIELS: So I guess we have more time to talk about our own ideas about things that need to be in the plan but I wanted to just make sure that we discuss public comment. Is there anything else that people have to say about the public comment that came in?

DR. TAYLOR: I mean I think - this is Julie Taylor, something that comes up over and over again that I think will need to be a piece is just the lack of adult services…

MS. GOODMAN: Yes…

DR. TAYLOR: …and that was in the last plan and it's in this plan and it will be in the next plan. But if I look at one theme that seems to be coming up over and over and over again in the public comment, it really is just the inadequacy of the adult service system in terms of funding.

And in terms of the availability to be able to meet the needs of these individuals and that's probably going to get worse, right, as more and more people with autism become adults. So I think that is going to need to be kind of front and center in terms of incorporating in the public comments.

MS. GOODMAN: Right.

DR. DANIELS: Anything else on public comment?

DR. TAYLOR: Is it possible to quantify how many people commented on this section compared to - what did you say the 1100 that commented in general?

DR. DANIELS: It is possible, I don't think I have those numbers in front of me at the moment but we can.

MS. GOODMAN: Okay.

DR. DANIELS: We imagine that a lot of people went through the request for public comment and filled in something in every category. So across all of the seven questions but there may have been some people that targeted particular questions and left the others blank. So for the most part we've probably got a fair number of comments in this section.

DR. TAYLOR: Thank you.

DR. DANIELS: All right, so not hearing anything else regarding public comment we can move on to the next section of our agenda where we're going to talk a little bit about research progress. I've provided you with a list of topics for the strategic plan update as a starting place.

When you do your write-up it will need to be divided into a relatively small number of categories just because it is really difficult to read if you have 25 different categories and ten pages it will just be a little bit difficult to read and so we'll try to come up with some ways to group the information that is going to be readable and understandable and I'll work with the chairs on that.

But just to get started we have a list of some topics and so the ones that we have on the list are transition to adulthood, secondary education, vocational services, employment and financial planning, housing, community integration, social and recreational opportunities and inclusion. Long-term supports especially for high needs individuals and I think caregivers, or care giving, could be added there.

Health and healthcare, safety and adult diagnosis and then within those we've listed a few themes that have come across as we talked with the working group and in previous strategic plans considering access to services, the quality of life for adults, large scale studies of adult outcomes, self-direction, autonomy, person-centered planning and choice. Having a supportive environment, coordination of care across service systems and assistance with navigation across service systems.

So those are kind of cross-cutting themes that have come up and so thinking about those areas, I'd like to be sure that we touch on both progress that's been made in research and changes in policy and services themselves and so first let's talk about research. Are there some notable areas of recent progress in this field that you want to make sure get included in the strategic plan as major updates or changes in how we're thinking about adult services?

MS. CRANE: Susan?

DR. DANIELS: Yes?

MS. CRANE: This is Sam Crane, I don’t have an update but I was just looking at the categories that you listed and I know in a previous call we had talked about long-term outcomes of interventions including interventions that start in childhood. So, it was kind of unclear whether those would be in Question 6 or Question 4 and we decided Question 6, does that fit under any of those?

DR. DANIELS: I think in terms of the theme of the large scale studies of adult outcomes, I mean I think that that theme…

MS. CRANE: Right, could include…

DR. DANIELS: Yes, we could say something about outcomes related to interventions although I think some of that also might be covered with Question 4 so we'll just have to figure out where that fits best.

MS. CRANE: All right, thank you.

DR. DANIELS: Thanks.

DR. PEÑA: Susan, this is Edlyn, I just had a quick question to clarify the second bullet in the document says Secondary Education and I'm wondering if that's meant to refer to post-secondary education after high school.

DR. DANIELS: It should have had both or like you know, the - I guess we were trying to cover the whole transition period.

DR. PEÑA: Okay, got it.

DR. DANIELS: So yes, post-secondary education should be on that list too.

DR. PEÑA: Okay, thank you.

MS. CRANE: For research updates, this is Sam, I would - I think the Drexel study on getting a baseline of people's - of outcomes especially meaningful sort of quality of life outcomes for adults was really, really helpful. I would include that.

DR. TAYLOR: Yes I would too. So this is Julie Taylor and I see - I think probably from my opinion, the biggest kind of update that we've had in understanding adult outcomes is not only the Drexel studies but a number of cohort studies that I think have really carefully across the studies defined what are some of the major difficulties and issues.

And when I started doing this work in 2011 which was not that long ago, we knew almost nothing about employment and post-secondary education and living arrangements and all of these different things for adults with ASD. And now I think there have been some large studies, there have been a number of cohort studies that have really dug in a little deeper at some of these issues.

And I think have seen remarkable convergence across states in the countries, across countries, across ages, in terms of difficulties faced by many of these adults and I think that has actually - being able to define the problem in a really careful way and understand what the needs are I think has been a really major advance in terms of what we know about adults with ASD since the last plan.

DR. DANIELS: Julie, are there new opportunities that you think have emerged based on some of those findings?

DR. TAYLOR: Yes, I think it can go a lot of different ways. I feel like that is really only the first step in understanding what's going on. So I mean one obvious one, and I think one path that a lot of people have taken is to move - take those opportunities and the information that we've learned and move straight to intervention.

But, I think that's only one area that we could learn more. I think there's a lot of work to be done in terms of understanding maybe which of these areas of need are the most impactful ways to intervene in terms of understanding quality of life.

We can learn a lot more about mental health and not only the way that that impacts employment and post-secondary education but the vice versa; the way that all of these different activities impact mental health. I think there's a lot to be learned in terms of individual differences within the autism spectrum - really breaking down who seems to be most at risk, what that means for them and especially focusing in on maybe some of the risk factors that we could do something about.

I mean, a lot of the research suggested that if you're early language, it's not so good or if your IQ is a little lower, or even if your family has lower income that you're going to have worse transition outcomes but we can't really do a whole lot about that, right?

So thinking more creatively about other aspects that we can actually do something about. So, I think that there - I think we have a good base. Also, understanding which services seem to matter the most in terms of improving outcomes. We don’t have that information either. So I really think that there's a lot still to be learned from cohort studies and from descriptive studies pushing beyond just describing the problem and really understanding how to improve outcomes in a deeper way.

In addition to the actual intervention research that's going on to test out different ways to improve outcomes. That was a long answer, I'm sorry.

MS. CRANE: This is Sam, I would also add you know, a lot of the studies that we have including the Drexel study are somewhat homogenous in terms of the socioeconomic background and the racial composition and I think that we should definitely also include some - expand those to include a lot of different demographics and see if we can determine some differences because they're not necessarily things that we can change but people in different situations might need different services and might be facing different problems.

DR. TAYLOR: This is Julie again, I think that's a great point and another issue with the Drexel and most of the other studies is that a lot of them only look at what's happen at one point in time in terms of when we happen to catch you at this particular moment. Are you working, what does education look like for you? But clearly that's not the whole story, right?

So having a better understanding of what these trajectories of outcomes look like over time, who seems to be finding their way? You know, maybe some people it takes a little longer to find your place, right? And maybe for some people things are getting worse over time but we all know that when people develop, things are growing and changing constantly and understanding those patterns and how to put people on upward trajectories over time I think is something that we know very little about and I feel the next step for some of these cohort studies.

DR. CHEAK-ZAMORA: This is Nancy I was going to add that thinking about the comments about autistic perspectives, I think there has been a lot of new work in getting people with autism to actually be included in the study and in participating in the design of the study. I know Aspire has done a lot regarding that and we had a few studies at the University of Missouri including autistic people as well.

DR. TAYLOR: It's really important.

MS. CRANE: The Aspire study because that's also really crucial from the education, healthcare perspective, I'm sorry. They had some really, really good assessment of the state of healthcare for autistic adults.

DR. TAYLOR: And even thinking about quality of life to - you know, it's hard to figure out what is related to good quality of life for adults with ASD without actually asking adults with ASD, right? You can ask parents to find that but if we're going to really include a focus on understanding how to promote positive quality of life, as a factor either independent of or in addition to kind of employment and these other things then we just can't really do that well without including in some sort of autistic perspective.

DR. CHEAK-ZAMORA: Right, yes and I don’t think we have much of an understanding of what that is either.

DR. TAYLOR: Yes, I would say almost none.

DR. KLINGER: This is Laura Klinger. I also think that the idea of trying to not just look at outcomes for individuals with autism as if that's all one group but instead to try to look at, you know, thinking about autism as more than one disorder or along the spectrum and what are the outcomes and needs for different individuals along the spectrum is important.

The quality of life for example is a great topic and what you might think about quality of life for somebody who's more severely impacted either intellectually or by their autism, those outcomes may - best outcomes, may look different for other individuals on the autism spectrum. So maybe thinking about how to take some of our cohort studies and fine tuning them around specific kinds of autism.

MR. PARNELL: I like that idea.

DR. TAYLOR: I think that's great Laura and you know, these are things that I we haven't done very well within the research community because they're hard…

MR. PARNELL: Right…

DR. TAYLOR: It's really hard to figure out what quality of life means but I think we're at the place in terms of our base understanding where that's where we need to move now. At least in terms of one direction that we should be moving and kind of cohort the studies and descriptive studies to kind of start pushing in that direction instead of just redefining the problem in a more general way over and over again.

DR. KLINGER: Well, I think kind of related to that is the idea that in order to move forward with this next step, we're probably going to have to combine across cohorts. The one cohort of individuals is enough to describe outcomes for a large group of individuals with autism but if you're going to try to take different kinds of autism and look at outcome for parts of your cohorts, you're really going to have to do some large scale collaborative studies across sites.

And I think that's a really nice sort of forward-thinking mission for this committee; what would that look like, those kind of large scale collaborative studies. We don't see that happening right now, we've got some really nice data from individual cohorts but now what would it look like if we looked across cohorts?

DR. TAYLOR: And I think that would be the kind of specific recommendation and I correct me if I'm not right about this Susan, that would be the kind of the specific recommendation that I think we could make would be to recommend for the resources, you know, for a study to be able to do this.

DR. DANIELS: Yes and so do you feel that the infrastructure has been built and that you can just build on existing infrastructure or do you think that the infrastructure isn't there yet?

DR. KLINGER: I think cohort studies there are. I was working on a manuscript this morning so I've just this morning reviewed all of the different cohort studies and there's actually quite a number of cohort studies coming out and so there is some infrastructure that was not there at all the last time this report came out that needs to be built upon. That isn't to say that there's not room for additional cohorts but I think there's some really nice opportunity to combine across some of the cohorts that are out there.

DR. BISHOP: Laura, this is Somer, I really agree with you about building on the existing cohorts. I do think though because we just have such drafted cohort affects, that we're going to have to also create more modern cohorts of kids who have been diagnosed in the last 10 or 20 years because they're just likely to be a different group.

But then that will just so much add to what we have in terms of the existing older cohorts which also are still important to follow. And I think related to that we need to get away from even thinking about traditional outcome studies because it's not like your outcome stops at 25 and so even conceptualizing that as outcome is a little bit misleading when hopefully you keep developing until you die.

And so how do we build that into our language and thinking about beyond the transition to adulthood, once you're in adulthood and middle adulthood and later adulthood, thinking about, you know, progress and outcomes and needs throughout the whole lifespan too.

DR. KLINGER: This, Somer, I think that's a really excellent point. I think one of the critics we hear all of the time about our teach cohort is that this is a group of individuals who are in their 30's to 50's now and they're not likely representative of who the next cohort of 20 and 30 year olds with autism are going to look like. On the other hand, they are representative of what the first group of sort of aging and autism is going to look like so the idea of multiple cohorts representing different age spans I think is really important.

DR. DANIELS: Any comments about research in any of these other particular areas on especially I guess safety. Have we gotten anywhere with safety? There's the issues that we have listed are wandering, self-harm, criminal justice issues and victimization but there could be many more.

MS. CRANE: I would say that on wandering there's a real like - so far right now what we have is just some studies that say, you know, that people wander. And they're mostly based on parents reporting. They're not very good at distinguishing from situations where a person is not where they're supposed to be but they're not necessarily unsafe and situations where they are in fact very unsafe. So, you know, the wandering studies that we have so far, you know, you could either have just gone next door to the neighbor’s house and people are upset because that’s not where you were supposed to be or you could be, you know, in the river and there's a real concern about that. And then there's not very much on intervention from the perspective of safety rather than from the perspective of reducing search times or other things along those lines.

DR. TAYLOR: So this is Julie again, this sounds to me what you're saying like the same issue that we're talking about with the kind of more adult outcome-y cohort study type of literature where we're starting to get a good handle on sort of descriptively what's happening on a wider - sort of the prevalence of wandering or victimization or even criminal justice issues a bit. But, in terms of a deeper understanding of why and what exactly is going on that I think can lead to really well informed interventions is what we don’t have. Would you agree with that?

MS. CRANE: Yes, and I would say that it's even a little bit less robust than what we're seeing in the adult outcome studies because the word wandering means so many things that we can't even really say how many of the people that are reported as wanders are having significantly worse safety outcomes.

They're not selecting for just situations in which the person was significantly unsafe. They're talking about all situations where the person was supposed to be on place and went somewhere else.

DR. KLINGER: So this is Laura Klinger and I think one of the things that you're suggesting that I think is true across multiple of these categories is we actually don’t have good measures. We don’t have good measures to define what we mean by wandering. We don’t have good measures around what we mean by quality of life, we actually are really struggling with measurement across all of these different topics. I don’t know if that makes it a topic in and of itself or something that needs to be considered across topics but the lack of good quality measurement will impact the meaningfulness of the results that are derived from research across any of these topics.

MS. CRANE: I would agree with that.

MR. PARNELL: I would too.

DR. CHEAK-ZAMORA: This is Nancy. I agree. I was also thinking that when I - at least I'm asking and I've read that people ask these safety concerns were often asking the caregivers if they're worried about these safety issues and that's almost always yes. But then when I actually try to see if there was an occurrence of victimization or sexual violence, that doesn’t actually happen very often or at least we don’t record it very much. So I think that there is this divergent between what we're scared about maybe and what's actually happening although the potential is certainly there.

MS. CRANE: Well, and it's not - I mean, so if someone is worried about sexual violence, that's a very big - that is very different from - often (unintelligible) outcome that definitely - that I know happens a lot but I don’t think it's associated with wandering. You know, so, people will say, hey I'm worried about safety but we don’t know what exact - we don’t know how often wandering is associated with a negative outcome, we don’t know which negative outcome those are when they do happen.

MS. GOODMAN: Right.

MS. CRANE: And we don’t know what - when we do have sexual violence, we do have actually a few good studies outside of the autism field in the broader (DD) field that show that for example when people have better education about sexual health and when people have better autonomy over their lives, they are safer. So I don’t know if that's happened in an autism specific study, I'm not even necessarily sure it needs to happen in an autism specific study.

DR. CHEAK-ZAMORA: I agree, it hasn't right? I think we know that education particularly on sexuality is low but we don’t have that data to say that if we increase education how that would change in outcomes. And that's also a quality of life issue too.

MS. CRANE: Well, because that also how people end up building relationships and meeting their own personal goals.

DR. CHEAK-ZAMORA: Exactly, yes. I totally agree with that.

DR. DANIELS: Do you have any specific comments about research on vocational services, employment, financial planning, housing, community integration issues, anything like that?

DR. KLINGER: I don’t think we have very much research on those topics other than to give sort of general results in terms of the percent on employment or the percent needing support for community inclusions. I don’t think we've reached the stage of research to really look at what Julie was saying earlier, we actually don’t know which factors are most associated say with the ability to have sustainable employment and we don’t know what the best intervention approaches are to help with sustainable employment.

So I think both looking at sort of predictors and correlates has not been done extensively and then also looking at intervention services, it's not been done. To me those are kind of black holes of in the research literature.

DR. TAYLOR: Yes, this is Julie, I agree with that and I don’t think we've taken a really careful look at the services. I need to be restating what you're saying Laura, that the services and what seems to be where we can get the most bang for our buck in terms of investment services because really I mean we don’t spend nearly enough money on adult services but the government spends quite a lot.

And so if there - but yet we're not seeing - we're still seeing outcomes that are not what we would like to see and so if there - we really don’t have any research to help us more carefully figure out where to be putting more of the money, maybe versus money - less of the money or for more targeted groups of people to be able to, I think more efficiently and more effectively and more critically use the services and the funding that we do have for services. I mean, there's just almost nothing like that out there.

MR. PARNELL: This is Brian and I agree with all of that. I think maybe some of the reasons for it is that the service provision and history is just now changing from process outcomes to actual outcomes. So contracts, for instance, in the past have dictated that the company is providing employment services, move people through particular service plans and different activities, without really requiring an outcome.

We may have people in services for two years, three years, in job preparation but not a lot of monitoring taking place for whether or not that person ever achieves employment or supported employment or partial employment.

MS. CRANE: And one thing that we sometimes see those effects of studies in the broader (DD) context and so a lot of people are using studies that are, you know, focused on people with developmental disabilities in general or people with intellectual disabilities and so I don’t want to - because people are using those studies, I think, in the meantime but I agree, I don’t think there's any autism specific ones. I think it would be very useful for people to look at the ones on other developmental disabilities.

MS. GOODMAN: Right.

MS. CRANE: You know…

DR. TAYLOR: That's a good point.

DR. SUSAN WHITE: Hi, this is Susan White, can others hear me?

DR. DANIELS: Yes.

DR. KLINGER: Yes.

DR. WHITE: Oh good, I've been on the call for like a half hour but I think nobody could hear me so I hung up and called back in so I'm sorry. I'm just going to try to summarize some thoughts that I've had but obviously wasn't successful in speaking to add into this. When we're talking about the topics here, somebody had brought up, I think it was Susan, about the safety issue and I do think there's been quite a bit of research on driving and driving safety there especially with virtual reality and kind of the exploitation of more computerized interventions, not just for driving, but for a lot of safety related kind of concerns. So that's one area that I would add to this.

Also I was a little bit surprised that we don’t see more on this in terms of this feedback from the community or on this list for pharmacotherapy intervention. And I get a little bit concerned talking so much about services and not treatment intervention.

DR. DANIELS: That's a separate chapter that's all about treatments and intervention.

DR. WHITE: Right, right, and I just want to make sure there's, I guess, crosstalk going on because it's also for adults. So I guess my bigger concern is really assessment within adults and then looking at - so much of it what we have focused here in our bullets is early adulthood when hopefully adulthood expands many decades and change during adulthood and I think maybe Julie was bringing up that point earlier but it's not just for the 20's or the early 30's.

MS. GOODMAN: No.

DR. PELPHREY: This is Kevin Pelphrey I just want to echo that statement about the adult treatment and intervention, I chair the Intervention Subgroup and so that's something that we're very interested in building within that subgroup, we'll get that in the chapter (unintelligible) and really talking about simply emphasis on early intervention but other points, development (unintelligible) where there might be exceptional (plasticity) to take advantage of in terms of intervention.

DR. TAYLOR: Kevin, this is Julie, as we move forward in this we'll have to talk more because I think there are probably places in both of these chapters for that because I think, you know, these interventions and therapies and psychopharma - all of that stuff is going to matter a lot for services and adult outcomes and things too. So, we'll coordinate.

DR. PELPHREY: Definitely. Yes, and I think it’s such a win for our community (unintelligible) early intervention but even when we were discussing the comments earlier about somebody had written in the comments we should just focus on early intervention. I think the part that reflects a great extraordinary success of kind of selling early intervention if there's no - no really good reason why there are great opportunities for interventions in adults.

So, I think the (unintelligible) is catching up to the idea that there are multiple opportunities for the type of plasticity)that people find in early intervention. So we should definitely coordinate and send a (unintelligible) message.

DR. TAYLOR: And I actually think we need to make sure that we're talking about that when we talk about advances in the field since the last plan too. And that - I mean, we have a long, long way to go in terms of designing effective interventions but there's much more intervention research in adulthood than there used to be and some of that is a direct result of the last strategic plan, right?

Some of the serve ASD R34's that came out from that really brought people either interventionists into the adult area and the transition area or people who were maybe thinking about doing interventions but hadn't quite jumped on the intervention wagon yet into actually thinking about how to take some descriptive research findings and turn them into programs and intervention.

So, I think there's a - I mean, an infinite amount yet to do but at the same time I also think that the interventions and programs for adolescents and adults is also a pretty big advance since the last plan.

MS. CRANE: On the other hand, this is (Sam), I'm not entirely sure where we're drawing the distinction between interventions and services because a lot of these things like supported employment, institutional training, supported housing or our interventions unless they're helping a person develop skills that they're going to be using for independent living.

So, there are going to be some things that, you know, would be considered interventions if it were a child but because one reason or another a person is an adult and they're getting this from the homing community-based services program it's classified as a service.

DR. PELPHREY: I mean, that's a really good point and it's worth in terms of talking about policy where you're talking about one reason why a (unintelligible) services is because (unintelligible) and so there's less of an emphasis on treatment and intervention and more on services and support and I think that we can help educate (unintelligible) to make and really understand at multiple levels how those services that are really intervention help to allow the individual to facilitate their own continued development. There's a lot of very interesting science about that.

DR. KLINGER: So this is Laura Klinger, I - and Kevin I think that was you talking and I'm not sure I heard all of what you said but what I think you said was that we kind of need to look at the issue of the interventions that are being used in the service industry.

So I don’t know that if you look at large scale service systems say like vocational rehabilitation and supportive employment services. I don’t know that the services that are being provided to adults with autism are based on intervention research suggesting that those are the best services for adults with autism.

I think the service industry has tried to use the approach that's been longstanding that wasn't really developed around adults with autism and I think the struggle is what are the best interventions for adults with autism that our service delivery system should be using. I don’t know that we have good quality research yet to answer that question.

MS. CRANE: They have - this is Sam Crane again, they have some pretty good quality research on this for individuals with intellectual and developmental disabilities. So another situation where you would want to have some coordination between autism researchers and the IDD researchers and say like, okay, what are some promising practices in your field, can we maybe do a study to confirm that this is working for autistic adults as well specifically and does it need to be tweaked in some way.

DR. KLINGER: That's right and I think the issue of the autism spectrum being so broad is that if we try to use the - to deliver services, that we're developed around an individual with an intellectual disability is that the best fit for services for adults with autism who don’t have a co-morbid intellectual disability?

((Crosstalk))

DR. DANIELS: So does anyone have any comments about adult diagnosis? This is something that came up in the Question 1 working group and this topic will be somewhat covered here also. They were talking about whether it's a benefit to get an adult diagnosis and whether that's adequately linked to the service system; any issues around that. Do you have any comments on that?

MS. GOODMAN: Yes, this is Amy and I think that adult diagnosis is important because a lot of people get overlooked. I myself wasn't diagnosed until my 30's so, you know, it's hard to know what's going on in your life if you don’t have a diagnosis. It kind of puts closure on something that you've been looking for, for more than 30 years and it gives you some place to start with your life. If you know what you're dealing with.

MS. CRANE: I would second. This is Sam, I think that's totally true.

MS. GOODMAN: So…

MR. SCOTT BADESCH: This is Scott Badesch, I'd also add that particularly with government benefits including the (unintelligible) and we're trying to get the age extended, it would be good if it was in the document.

MS. GOODMAN: Right.

MR. BADESCH: And then reinforced there.

DR. TAYLOR: So for the clinicians or the people who have more experience with adult diagnosis than I do, what are the barriers? Is it measures, is it finding providers, all of those things?

((Crosstalk))

Dr. White: …third-party reporters. Specifically the parents.

DR. TAYLOR: Who is that talking?

DR. WHITE: Sorry, this is Susan White. I was saying a lot of our measures, especially for the more impaired individuals, it's really hard to get a reliable diagnosis and a differential diagnosis when you can't have a third-party like when parents are deceased.

DR. BISHOP: Yes, this is Somer Bishop, I total agree. I think we have major measurement limitations; both from the caregiver report side of things and the director report side of things because we just haven't studied this group of people nearly as much and the differential diagnosis thesis is particularly troubling for people who are presenting for the first time when they're older.

Because a big part of the diagnosis has traditionally been history and if those people aren't available or if they - or if the measures aren't working in a valid way then we rely on direct observation and then I think the number of people, the provider issue, is that the people who actually have experience diagnosing adults and being able to differentiate ASD from other disorders that present in adulthood is really, really limited.

MS. CRANE: Another thing with third-party reporters is that often, you know, and this is going to start happening more and more with the next generation of adults is that if someone made it to adulthood without a diagnosis, there might be a reason and one of the reasons might be that the parents are on the spectrum themselves, they think of a lot of things as normal, they're not going to necessarily be reliable reporters on whether their child was outside the norm on a lot of these things because they…

MR. PARNELL: Yes, that's a wonderful point.

MS. CRANE: …another kid and they just never really noticed anything going on.

((Crosstalk))

DR. KLINGER: I would agree that this issue - this is Laura Klinger, this issue of adult diagnosis extends beyond adults who were receiving a diagnosis for the first time. It extends into access for service delivery as an adult that most funding agencies require a reevaluation and there are very few ways for us to reevaluate symptoms of autism in adulthood and also the way that that's been done in the community is through a self-report questionnaire.

And we don’t really know if that's the appropriate way to diagnosis autism in adulthood. I would suggest it probably isn't the appropriate use of some of our self-report measures. So I think it's not just around the issue of diagnosis adults who were never diagnosed, it's a huge issue for access to services for individuals who were diagnosed as children.

((Crosstalk))

DR. CHEAK-ZAMORA: Those of you who are clinicians, correct me if I'm wrong, but I also get the sense from people that we've seen in our labs that I don’t know that we have a really good feel for even what the range of what autism looks like in adulthood. We've seen people who have come into our - into some of our studies and we do whatever our current instruments are to confirm their autism diagnosis and it may look like they don’t meet current criteria but then you look at a videotape of when they were little and they certainly did at that point.

So, what does that mean? Is it - I just don’t know that we have had enough long-term studies… I mean, this goes back to sort of the long-term studies of kids who have been carefully diagnosed.

DR. KLINGER: Well and I think - this is Laura again, I think that what you're suggesting is that above and beyond the question about diagnosis, this issue of measurement in terms of the support needs, so for example, do we have a good measurement to look at executive functioning skills that are necessary for adult life? Do we have a good measure of daily living skills for adults with autism?

So beyond the question of diagnosis, how - what are our measures to document needs for adult services? And I think that's where we are really struggling. So clinically, diagnosing an adult is one issue but beyond diagnosis when we're accessing for services we need to say where the adult needs additional support and we have very little in terms of good measurements for that.

MS. GOODMAN: Right.

MS. CRANE: We also have a really have a really hard time - and this connects to the Question 4 issue, we'll see some studies of early interventions where the target of the intervention is essentially to reduce the appearance of autism in the child and so you'll get someone who's done very intense interventions that are almost calculated to make it more difficult to recognize that the child is autistic when they reach adulthood.

But, even though it's not necessarily going to be apparent in an hour-long interview or a half hour long interview, we're still seeing people who have significant executive functioning problems, anxiety problems, difficulty maintaining social relationships, difficulty maintaining - they are definitely still disabled but they're not going to be checking off all of the markets are the tests that are developed for children.

MS. GOODMAN: That's true.

DR. DANIELS: So are there any - this is Susan, are there any unintended negative impacts of getting a diagnosis when you're an adult, and impacts on services?

((Crosstalk))

DR. DANIELS: In the current system is there - are there any downsides to getting a diagnosis? This is something that Question 1 folks were interested in exploring but felt maybe this group would be better to address it.

DR. TAYLOR: Are there some employment opportunities that you would not be able to pursue if they knew that you had a diagnosis of autism? I think that would be the biggest…

DR. PELPHREY: One of the - this is Kevin, we were recently doing some research to try to understand employment opportunities besides the security field (unintelligible) and one of the roadblocks there is with a diagnosis depending - but in general securities there is more difficult to achieve if you've had a history of a psychiatric diagnosis.

These things are changing in particular like with autism, but certainly still something that gets additional scrutiny and I think the number of (unintelligible) that have been (referred) really change individual (life) based on mental illness, classified as mental illness depending upon data.

(Unintelligible) worry me in the sense that limiting opportunities for people who are already significantly under employed and limiting individual rights guaranteed (as citizens) based on those types of diagnoses. So I guess that from that perspective, that's something that I think about as a parent in terms of my daughter's diagnosis and thinking about better serving adults with autism.

So, it's something - as far - I think the benefits far outweigh the costs but it is something that we could be of assistance with in the field in kind of changing that perception.

Ms. Crane: This is Sam. That reminded me of parenting as well because one of the most significant situations in which we see adults having a diagnosis used them against them has been parenting and custody chases. And that's another area of adulthood that we have almost - I mean, I can zero research on is parenting when you're on the autism spectrum and it's a big part of adult life.

But a lot of the time people do sometimes have, you know, lose custody of children in part because of the autism diagnosis. So that - independently of any objective issues with their parenting, that sometimes gets used against them in court. So my…

((Crosstalk))

DR. TAYLOR: Go ahead.

DR. PELPHREY: I was just (unintelligible) that comment.

Dr. Klinger: My question has to do with the military and I honestly just don’t know. I've had several families have concerns about whether a diagnosis of an autism spectrum for their young adult with autism would prevent them from being accepted into the military. That's the only condition and case in my sort of experience with diagnosing adults. I don’t know the answer to that but that would be a negative for some of our adult without intellectual disability.

MS. CRANE: I think it does and I think there are some people who have pilot licenses denied as well but they're appealing that.

DR. KLINGER: So I think the military issue in terms of the - you know, NIH sort of strategic plan, I think the military issue might be one that would warrant some attention I just don’t know very much about it.

DR. PELPHREY: I can tell you, you know, based on those that are curious, this is (Kevin) it excludes you from anything that requires a security clearance, again, so essentially any special forces, intelligence, anything above - certainly prohibit your ability to achieve a higher rank and I think it's changing slowly that it would outright keep you out of the military. And so there again, it's - since we don’t have the draft anymore, it's not seen as a positive but at one point getting any type of enrollment diagnosis would happily exclude some people from military service.

But, you know, living now in Virginia Beach where we have one of the four places where people can be assigned if they have a child with autism, it also affects the view of the parent so if you're in the military and you're military and you know that if your child is diagnoses with autism, it limits your order for location. That seriously constrains your ability to move up in your career so I would imagine if I were told I could only move to one of four universities based on a diagnosis, I would be kind of outraged but we accept this for our military families.

I venture - I just got out of (unintelligible) the other day so I (venture) that I'm the only one that knows this. On the (unintelligible) committee because it's not talk about but that's the part where (unintelligible) that our military families are treated, it severely limits their opportunity.

MR. PARNELL: This is Brian in Utah and being from here, I've seen that there's some real stark parallels to religious participation also having to do with an adult autism diagnosis. In the LDS church, young people often go on two-year missions and I've seen people who are wanting to participate in that mission activity who were excluded from the ability to do that based on their diagnosis. That also I think is changing.

The LDS church is getting better at making accommodations for mission assignment of keeping people in state or close to their supports but it definitely sometimes has an effect on their ability to participate at all.

DR. DANIELS: Thanks for giving these issues some careful thoughts and more might come to you as you work on writing about this but it seems like there were some concerns about both the pro's and con's and being able to do what we can as a committee to remove barriers.

DR. BISHOP: Susan, this is Somer again. I'm not sure, this may be way to peripheral so you can just disregard if so but one of the things - one of the other gaps that's just emerging I guess in our - well it's becoming more apparent in the literature and in clinical practice is that more and more of our adults are getting entwined with the legal system for various reasons and we don't have really the research to support what to do or the measurement to really know how to deal with this too.

So, I mean for example clinicians are being asked to consult in cases on whether somebody can be executed due to an autism diagnosis. I know this is a really different kind of question so that's one aspect of the legal system but then also just people with ASD being put in jails for a variety of reasons or having needs that involve the legal system. So, I don't know if we're supposed to deal with that at all but that's just something that I'm seeing a lot of in clinic.

DR. DANIELS: That is within bounds here. And just as a clarification, it's not an NIH strategic plan, it's an inter-agency autism coordinating committee strategic plan that's providing advice to all of the federal agencies.

DR. BISHOP: Okay.

MS. PRINCE: And as much as that conversation - this is JaLynn Prince, I talked with one of the attorneys general in Ohio and he was talking about how many people had come before him that were on the autism spectrum and often with inadequate legal defense and he said that there’s a lot of people that he is aware of on the spectrum that probably should not be incarcerated but there’s nothing legally that he could do.

MS. GOODMAN: They just didn’t know what they were doing.

MS. CRANE: I think that’s especially happening for people who were homeless, who are chronically homeless who’ve had a very significant issue for people on the spectrum and also a lot of the time people of color on the autism spectrum when they’re confronted by police, they’re kind of targeted by police or police violence and for arrests for things like disorderly conduct or resisting arrest that really they shouldn’t have.

They shouldn’t have been in this situation but (if that but) if we had better policing and better informed policing, that shouldn’t have happened at all. I don’t think disparities are important to study.

MR. PARNELL: Yes, and just to dovetail onto that, I think that also extends into the system of public defense attorneys because once a person gets arrested, it’s really their defense attorney’s job to raise issues of competency for being prosecuted for crimes.

MS. CRANE: So I’m not talking about classic competency issues. I’m merely talking about situations where we’re seeing biased policing that is targeting people for things that really aren’t even (unintelligible) even things that are complying.

MR. BADESCH: Well, this is Scott Badesch. We also see a lot of individuals with autism arrested because they didn’t understand their rights, police taking advantage of people because they’re autistic to get evidence. It’s a major thing. I like the idea of the research but I think it’s not just the courts. It’s from the moment of interaction with the police evidence.

((Crosstalk))

MS. CRANE: I think that that’s just the first point and homeless, I mean, homelessness and drug abuse and other, you know, negative outcomes that can really also impact that.

There’s a lot of homeless people in the autism section and you know what people who are homeless are going to be targeted by police and people on the autism spectrum who are targeted by police might not know how to respond or they might be responding in a way that makes police suspect they’re on drugs or something like that because they just …

((Crosstalk))

MR. BADESCH: But you also have the issue of a lot of the court system is just like when you read someone their Miranda rights, if someone takes that literally, we have a guy who said you have a right to an attorney and he knew his dad was an attorney, said why would I need an attorney?

So with that whole process of understanding your rights, understanding interactions, what you want, we have a guy who was arrested who had some evidence on a cellphone and he argued that when police said to see your cellphone, he didn’t know that they needed a search warrant at the time but they also thought he was asking him can I see your cellphone just like kids ask to see other kids’ cellphones so it’s a major issue.

MS. GOODMAN: Yes, yes.

MR. BADESCH: And it’s also an international issue. It’s not just here, it’s everywhere.

MS. GOODMAN: That’s good.

DR. DANIELS: So one final area on research before we just talk generally about services and policy, are there new opportunities in research that are based on technology that you think would impact services research?

((Crosstalk))

UNKNOWN FEMALE SPEAKER: Oh I think it could. I’m very well aware of three new programs underway that could include technology as prompting for more independent living and there’s actually one person that is doing a project to NIH that is centered currently on stopping smoking and behavior that they have been running some corollaries with perhaps autism about how to help with behaviors and have positive reinforcement.

So that was (perfect) combined with services knowing when services are coming-in with also understanding triggers for behavior. I think there’s some interesting things there for some portion of the spectrum.

((Crosstalk))

DR. KLINGER: I think there’s some opportunity to use technology in terms of service delivery around telehealth for families who were living in more rural areas so I think this is an issue across the lifespan that you could think about how we might be able to use some of our telehealth models to support adults with autism in areas that don’t have a lot of resources.

DR. TAYLOR: I just want to echo I think telehealth is across the age range but I think it’s especially poignant for adults because a lot of them don’t drive, they don’t have access to public transportation and a lot of them are very under-motivated to seek out treatment for themselves when they don’t have a parent who’s making the call and setting it up.

((Crosstalk))

MS. CRANE: And I’m going to say smart cars. I know that a lot of people are thinking that these are going to help individuals who are blind for example but I think that’s (unintelligible) the autism spectrum like the self-driving part.

((Crosstalk))

DR. TAYLOR: And I think Uber is working well to help in that arena as well prior to smart cars.

MS. CRANE: It’s not (super C) but yes, they’re working on the self-driving cars, that’s true.

((Crosstalk))

MS. PRINCE: I’m very concerned - this is JaLynn Prince again - I’m very concerned of the lack of medical research into this population. There is so much more understanding of say Downs and what life course happens to be and our population is much larger than the Downs population but there have been tremendous medical advances in understanding things.

Now I know there’s much more a homogeniality to some aspects with Downs. We’ve got a much broader range of individuals in many ways but we’ve got huge questions. What is the aging process and where are we and what are the implications for heart and blood pressure, mind dementia, societal compliance?

I mean, going on and on and on if your phase of life that those that are more prone to maybe aggressive behaviors, does that (unintelligible) perhaps in different age ranges and if so, to what percentage?

There's just so much that we need to know to be able to even think about living situation because right now we're talking about living situations very often for people who are quite capable and who may endure putting up with being involved in society to some degree but there's a lot of other people who can't handle that and do things change?

Is that something that happens when there's a change at 40 and that may mean that there would be different living accommodations that may open up and be more appropriate at that age? There are huge things and they all have gigantic implications on a federal budget.

MS. GOODMAN: Uh huh.

MS. CRANE: Well we know that a lot of the you know, housing projects especially the congregate models are you know, based on the idea of people sort of being in these groups, living situations that are much more common for 20 and 30-year-olds, even people without disabilities they're more likely to have roommates for example. As people age, they don't really like that very much.

MS. GOODMAN: No.

MS. CRANE: Wonder if that's, you know, people …

((Crosstalk))

UNKNOWN FEMALE SPEAKER: … sometimes the inverse that by the time somebody becomes 55, then we want a lot of people that are at that point in their lives. We see that in the general population and we have no idea, no idea whatsoever.

MS. CRANE: I’m mainly talking in terms of like the amount of, you know, personal space and the person’s tolerance for living with a person that they don’t know very well might it’s in their house so like a lot of the over-50 communities are, you know, you have family, you still have the assumption that you’re going to have a couple or an individual living in a house and the person next door is also a couple and their individual living in a house and you’re not going to have roommates.

UNKNOWN FEMALE SPEAKER: Uh huh, good point.

MS. GOODMAN: How about people who might want to live in their own homes …

((Crosstalk))

MS. CRANE: Right, exactly.

MS. GOODMAN: … I own my own home or at least I’m holding the mortgage, I mean, but then that also brings-up the idea of marriage I was thinking how much research is out there about people who are have ASD that get married or live on their own are independent.

UNKNOWN FEMALE SPEAKER: Yes, that’s a huge area to research.

Ms. Goodman: Yes, I just didn’t know how much research was out there.

MS. PRINCE: And, you know, I think you’re also sitting on something else too. I have been asked to work on a project at one point - this is JaLynn again - on sexuality and adults on the autism spectrum. I don’t think we’ve got the faintest idea and there’s a lot of assumptions out there and are they real?

Is there a proportion that that holds true for? Is there a proportion that another view is more relevant and so forth? We don't have any idea about general sexuality within our population.

DR. CHEAK-ZAMORA: This is Nancy and I would agree. We're doing a couple of small studies on that and I would say in the past five years there's been a lot of more survey work with people with autism, young adults and adults that are looking at sexuality issues but preceding that it was all acting caregivers and healthcare providers about young adults and adult sexuality.

So it's new but I think that they are working on it and we have, you know, that understanding is broadening slowly but surely.

MS. GOODMAN: Okay.

MR. BADESCH: This is Scott Badesch. I please don't take my comment as not suggesting it's research but we could research the heck out of this and everything and everything that's been said is wonderful but the reality is, you know, we got people on eight-year waiting lists for services and my concern is if we have this tremendously long boilerplate of research that's needed, how do we balance that with this tremendous need for services today?

If they quite frankly if research was done 10 years ago, we may be ahead of the game but, you know, everything that I'm hearing is great to do research and can name 100 other things that we could be valued on business I just get nervous when you know, I was in Florida the other day.

They have an eight-year waiting list for services and we're talking about more research. We've got to put something in there for services.

DR. DANIELS: Great transition to talking about services so this chapter's also going to just discuss services in general so at this point you can just talk about service needs, any progress that's been made in services, are there some great models out there that people should be looking at across different states? Anything related to services so …

((Crosstalk))

DR. BISHOP: If I can just add one thing to that, this is Somer Bishop so I think that's a really good point. I think one of the problems we're running into though is that it's possible that our service delivery is just really inefficient so when we don't know what people need or want, I mean, it really comes down to we talked a lot about individual variability earlier on and trying to figure-out matching-up what people are actually doing with how it actually makes them feel about their lives.

But things that when we are relying so much on assumptions about what we think people should want or should do according to kind of traditional paradigms of adult life, then we're really stuck because we may just be giving certain people who are getting services may be getting services that aren't efficiently delivered as they could be or that aren't relevant or related to their quality of life.

MS. CRANE: I find that generally when people are offered services that aren't related to their quality of life and aren't efficient or relevant to them, they don't need them so I'm not sure that there's going to be like all of these people who are getting tons and tons and services that they don't want.

And we know that these waiting lists are true for almost everyone with a disability across the board so I think that it's true, I mean, I think we really do need research on services to know which ones are the best ones to be delivering but we also just there are plenty of things that we know are affected and aren’t and people aren’t getting.

((Crosstalk))

DR. DANIELS: So Sam can you describe some of those? Are there areas where we do have a good research evidence base or other evidence that would lead to …

MS. CRANE: Yes, supported employment, I know that, you know, we were just talking about how we have very few models that are (unintelligible) specific but or, you know, a lot of people on the autism spectrum, if you combine the research on people with intellectual and developmental disabilities and you also you (unintelligible) supported employment for people with psychiatric disabilities.

There’s a pretty good…there’s a pretty good basis for thinking that supported employment is going to work for individuals on the autism spectrum especially people …

((Crosstalk))

MS. CRANE: … persistent difficulties relating to people in the workplace but if you have to wait for eight years to home and community-based services of any kind, you’re not going to get that.

MS. GOODMAN: Yes.

MS. PRINCE: In fact I have a question here, I would like to see more participation if we could at NIH with health and human services because that is I think a glaring deficiency in some of our conversations and participating in some of the conferences that have been around I think a lot of the policymakers formulating policy with a few opinions that may come across your doorstep.

But not looking at the totality of what really the need is and on paper some of the delivery systems may look fine but are really falling short, are inadequate in number, the (face) are confused, parents are confused and communities don’t know how to step forward with delivery of some of these things over the age of 21.

And it is becoming harder and harder with housing components and then getting people involved in the community and we keep hearing this rhetoric get out in the community and there’s a community but we don’t have from our fundamental government agencies realistic ways in doing that.

And also taking into consideration at times that our population not everybody in the population wants to be in the middle of community.

((Crosstalk))

DR. DANIELS: So…

MS. CRANE: So I don’t think that that’s even the beginning of the problem so I’ll just sort of take a step back and discuss this. There’s you know, in order to get any kind of home and community-based (unintelligible) you have to be on a waiver. Many states don’t even offer waiver services to people on the autism spectrum who don’t have actual disability.

If you do waiver services many of those services are regional only so they aren’t statewide. You might have to (unintelligible) the metropolitan a purchase to a metropolitan area within your state in order to get the services.

Then if you happen to move to another state, you have to get on the waiting list again.

MS. GOODMAN: Yes, yes, you have to start over.

MS. CRANE: Many people can’t move to be with their family, to be with their spouse, to pursue new job opportunities or to go to college because they can’t get on a new home and community-based services waiver and I think that, I mean, people will talk about well, people are being too forced to be in the community.

But I really don’t think that that is the main issue for almost anyone and receiving services that (you have these) waiting lists and the fact that the services aren’t even offered statewide and they can’t transport them from state to state and they’re not getting any help.

((Crosstalk))

UNKNOWN FEMALE WOMAN: Need to get this portability issue between states taken care of and I don’t know if the governor needs to be involved in this conversation because this goes into state (flyers) but we do need to adjust it somehow.

((Crosstalk))

DR. BISHOP: I think the portability issue is a big deal and I also think in terms of some of these things we’re talking about for housing and things of that sort, I mean, these are empirical questions that we could be doing studies on in terms of what are the impacts of, you know, being in the community versus sort of in other types of settings and who benefits more versus, I mean, we’re talking about I think a lot of us have really strong opinions about those things but these are things that we could be doing research on to try to tease this out from the data and understand it better and that work just hasn’t been done yet.

MS. GOODMAN: Right.

MS. CRANE: The other thing I will say is that a lot of the more congregate models that people discuss are, you know, I attended a presentation by a ranch in Texas. It's, you know, portraying itself as sort of an intentional community but it's licensed as an intermediate care facility and what that means, you don't have to …

((Crosstalk))

MS. CRANE: … you don't have to be or in a home and community-based services waiver in order to get into that facility. You just have to be on Medicaid in general. There's no waiting list at all so it's actually easier to get into that kind of a setting than into than to get into an apartment in the community.

MR. BADESCH: This is Scott Badesch. Could I - I think on the research element of adult services - I think the best research we could use is just to look at what's the job needs of our society five to 10 years and how do people with autism, what's the skillset that individuals with autism have that may meet those skillsets?

What we're doing with employment is we're reacting to today's employment needs and which are changing every hour and then the second thing I would suggest is that you know, it's no surprise to anyone that government doesn't fund services based on outcomes and so maintenance at best.

You know, so how do we at the beginning of this call we talked about outcome measurements and how do we, you know, what outcomes will lead someone into whatever it is that person wants to be?

What gets me nervous is we're doing a lot of work on how to find people jobs which may be great but if a person doesn't know how to be self-sufficient or independent or socialize or communicate, that really doesn't help.

So how do we achieve the outcomes, the quality of life outcomes and given what’s going to happen in five and 10 years with our society and everything, how do we adapt people with autism to that need? You know, and as far as portability and all that, you know, it’s not happening. I mean, every one of us have tried to figure it out with Congressmen but if we could show good data and good research, it may happen

There’s very little research to suggest the benefits to a state, I mean, states benefit when businesses bring jobs to a new state but if we knew that those jobs people with autism could more easily fill and be more successful than other people that may help the portability argument.

But there’s no why would a state want to, I mean, this is going to sound totally crass and I don’t believe what I’m about to say but states don’t want people with disabilities moving into their states so they have to fund so we have to find research to justify why it’s a benefit to the state to have those individuals come in there.

And then the last thing I would say is there’s not a lot of good research on the impact of government dollars in terms of taxable benefits to a community and jobs. You know, everyone knows that when we use government money to provide services, it helps hire people and that money stays in the community so why don’t we start doing research that could help those of us on the policy side have ammunition to fight the arguments that we fight every day?

And it’s all going to be based on investment. I know last call someone said they didn’t like the term, I don’t either but that’s the reality of government. They want to see their return on their investment and unfortunately return is not defined as them. The government policymakers was someone being better off in term of tax dollars.

DR. KLINGER: And Scott, this is Laura Klinger and I agree with quite a bit of what you said, thank you. One of the things that you said that I've been sitting here kind of thinking about is the idea that each of these topics that we have listed are not really independent of each other so …

MR. BADESCH: Exactly.

DR. KLINGER: … so locational services and employment for a person who doesn't have good daily living skills or doesn't have appropriate job-related social skills how do we put those together so I've been sitting here thinking if we were going to do an intervention study looking at say employment, well you would also need to look at maybe independent living skills which might be considered housing or you might need to look at social which might be considered community integration.

MR. BADESCH: Exactly.

DR. KLINGER: So the idea is that for me that the very best services are going to integrate across these categories and I'm a little worried about us putting them into these categories without an understanding that where this field needs to move is how we integrate across these categories. Our service delivery systems are delivered and funded separately and that's one of the problems.

UNKNOWN FEMALE SPEAKER: And one of the things that we're seeing and many parents have responded to this type of thing about what type of education now I'm not just talking about colleges education because Drexel is saying perhaps a third of our population goes on to (sue) college but I'm wondering if part of our wording may need to be education and not just life skills but life skills can be an education, you know, being educated on how to navigate life.

((Crosstalk))

UNKNOWN FEMALE SPEAKER - continued: … get a look at continuing education different models and how do we do that for over 21 where the typical college campus may not be the right environment but certain milestones could be reached if placed into the right environment or with the right people and the right support that asks for a process of three or four or five years, someone couldn’t be more productive in their work field and we don’t have many if any models of what type of thing to invest in.

MS. GOODMAN: No.

UNKNOWN FEMALE SPEAKER: But education I think goes right in with the typical population. I remember too I think technical colleges and different types of things which really help to put people into the types of jobs that may not be as fleeting as some of the things that I think Scott may be referring to.

There are certain things that are always going to have to be done and how do we educate people with life skills and job abilities and again it kind of comes back and the (hella thing) because where does somebody live for that four to five years?

And are we battling for an apartment or group homes or are there particular other environments that somebody could be involved in in an educational environment that would be parallel to the general population.

I know that these are big concepts being out there but I think we’ve got to look beyond look at the solutions and look at ways that we can nudge this conversation forward to accomplish what we would like to do and to be able to help people be enabled for employment.

MS. CRANE: And you know one of the things that people don’t know and this is back into actual college education but I know that we sometimes exist for other educational placement, new dormitory housing.

And I know a lot of parents right now when they’re looking at community college or college opportunities for their kids, there’s almost an assumption that, you know, autistic individuals can’t live in dormitories or this is going to be a scarier or a bad placement for them and if they have to live at home or in an off-campus housing but there’s no research on that.

There’s absolutely no research on what dormitory experiences of people who on the spectrum do live in kinds of (housed) dormitories and I remember someone presenting to the IACC on this about was that Edlyn, you know, parents who were, you know, helping their kids go to college who are on the spectrum and many of them were sort of productive lead placed in the off-campus housing or family home.

DR. PEÑA: Yes, and that complicate things even more fully with once you get somebody in a situation of into a group home and is that compatible with college and moving arrangements, yes, if we could have learning enters that may have a dormitory experience with them, I know I’ve got two other kids who went through it and tried and learned and learned from one another.

And knew that they weren’t alone, they know that others were going through this with them and I see a lot of people on the spectrum feeling much alone after 21.

MS. GOODMAN: Uh huh.

DR. KLINGER: So I think we have some models of that happening around the country but what we don’t have is any research going on, looking at those models in terms of whether that kind of support or that kind of housing opportunity whether that leads to, you know, increased emotional or more positive emotions, whether that leads to being more likely to be employed or being able to live independently so we don’t actually have research going on in those kinds of models.

But those models are actually popping-up all over the country so it would be and they’re not inexpensive models and so I think this is an area that it would be really nice to see some research on whether this particular sort of track is supportive. You know, it sounds good, it probably is supportive but we don’t have any research or any data, no publications coming-out on those kinds of models.

((Crosstalk))

MS. CRANE: … even just a regular dormitory, if someone is going to a college that’s for people on the spectrum had the dorms free, do we know, you know, what kinds of things will predict this person’s success to live in the dormitory with the other students?

DR. PEÑA: I would say we know almost nothing about what predicts …

((Crosstalk))

MS. CRANE: There’s nothing about it because it and so we do know that dormitory life is a very significant part of college especially if everyone else at your college is living in the dormitory is going to significantly affect your ability to integrate into the social life of the college.

((Crosstalk))

DR. KLINGER: So this is Laura Klinger again. Can I jump back to supportive employment because I heard somebody a little while ago say that we have really sort of good data on the fact that supportive employment works for successfully for adults with autism and I would maybe gently disagree with that.

We have a couple of studies that have been out recently looking at supportive employment, one study saying that national supportive employment statistics were 37.5% success for adults with autism in terms of employment.

And then more recently a study out of Drexel looking much higher at 60% but regardless somewhere between 37 and 60% of adults with autism who enter those vocational rehabilitation are employed, I would say that those are not really the numbers we would hope for.

MS. CRANE: So are you talking about vocational rehabilitation or supportive employment because those are very different things?

((Crosstalk))

DR. KLINGER: That’s correct, that’s correct. Those studies were both looking at VR. I think the issue of long-term supportive employment, that’s a completely different area with limited research in the adult area. The two studies that I’ve been recently looking at employment support were both studies of vocational rehabilitation.

MS. CRANE: Yes, I know, so the reason why I - this is Sam - I was the one that was saying that there’s a pretty good evidence base for supportive employment and the evidence base is mostly from studies on supported employment for people with broader developmental disability and people with psychiatric disability.

And you have to just you also want to look at the data that the supportive employment programs themselves keep so they aren’t necessarily going to be public research studies but you look at the programs, these sort of employment programs that are being piloted in many states, you look at their outcomes data that they keep they aren’t published in journals.

They’re more of the sort of public policy data because of this again this distinction in a lot of people’s minds between services and interventions and so they’re not …

((Crosstalk))

MS. CRANE: … if they’re considered services need to sort of have to …

MS. PRINCE: Yes, and this is JaLynn again. I wonder too, with some of these statistics you were quoting, we may not even have a definition of employment because are we talking about a 40-hour week, a 20-hour week, for an hour a week, and then …

((Crosstalk))

MS. PRINCE: … and its dreaded term on saying sheltered workshops …

MS. GOODMAN: No thank you.

((Crosstalk))

MS. PRINCE: … turn that totally on its ear and do something that can provide some individuals that may not find employment into a much more positive environment that is defined much more broadly. You know, I …

((Crosstalk))

DR. BISHOP: Yes, I think that was the point I was trying to make earlier - this is (Summer Bishop) - I didn’t do a very good job of it but that’s exactly what, I mean, I agree with that totally that when we’re talking about services that we need to know about the match for the individual that’s appropriate to really enhance overall quality of life.

And so it may be that for some people that 40 hours of competitive employment is the goal and then for other people that it’s a very different goal but we actually don’t have an empirical base for knowing what is asked for whom including, you know, including the employer and society and we’re talking about the cost benefit model.

So that’s where I think that this stuff does need to merge with the research to be able to really figure-out what individuals what we should be going for or what the goal is in terms of employment or any other kind of situation that we’re talking about for the adult services.

MS. CRANE: Even the most robust supportive employment outcomes research is going to be on people with intellectual and developmental disabilities so the group of people that we’re thinking are going to need like the most support are going to be are often when people are talking about that, they kind of they’re thinking about people who have autism and an intellectual disability or a significant functioning really significant functioning challenges.

And that’s actually the group of people that if you look at the broader developmental disability research on supportive employment, that’s the group of people that supportive employment is most well established for.

DR. TAYLOR: And Sam this is Julie. I think that that is I think that literature that we should build on in the document and I think we can cite it and I think it’s really, really important but I think we also need to make sure that we recognize that the social impairments in ASP that you may not see in some of these other groups is a really important factor that may make it more difficult for somebody with ASP and an intellectual disability to thrive in his environment.

((Crosstalk))

MS. CRANE: So that’s when you also have to I’m sorry, that’s why you also have to draw on the research that I mentioned on people with psychiatric disabilities including schizophrenia because they also have very dramatic psychiatric impairments. They also succeed in supportive employment …

DR. TAYLOR: But then they have the psychiatric issues and some of the that without the intellectual disability issues so I think we absolutely need to draw on both of those literatures but I don’t personally think that they compensate for the lack of research in AFC groups. I think there’s just more that we really need to know to be able to (get) a perspective but I do think that literature is very informative.

MS. CRANE: And, you know, I hear I would say (unintelligible) in a lot of cases you just have to use whatever and when you’re deciding what services to provide, you use whatever research is available. There’s no very good research on any intervention but you go based on whatever research is available and you make the best guess that you can.

DR. TAYLOR: That’s right, and then as a research plan here and what we were proposing then are to use that and then we propose next steps, right, for …

((Crosstalk))

MS. CRANE: Yes, I thought we were talking, I thought we had moved on to services.

DR. DANIELS: Oh, so yes, so this is (Susan). Just a couple of clarification points again. This is not a plan about NIH. It’s about all of the federal agencies and the different private partners that are working together on the IACC and what this group thinks are places that people can have more impact.

And that we are talking about both services and research. We’ve talked a lot about research and this was the time to talk a little bit more service delivery and policy. Are there any places where anyone in the group feels like policy changes or changes in programming could directly make an impact now?

MS. PRINCE: Housing. Housing.

DR. DANIELS: So what kind of things so give some examples.

MS. PRINCE: Well, right now we have a situation in this commentary so if you’re a lot of parents in communities that want to step forward to do some positive things but there are so many regulations and so many things that have been put together with good intentions that have not been examined closely enough to say this is stopping public and private innovation in trying to address these needs.

Right now people are scared to death to move forward to try to do anything innovative where research could even be gathered in fear that someone is going to come out and take away people’s funding.

And that is really at the heart of so many communities and parents and families and individuals that it is standing in the way of this country moving forward and making certain that there are appropriate choices in housing for those on the autism spectrum.

MS. CRANE: I couldn't disagree more, I couldn't disagree more. I think again as I mentioned earlier in the call there are so many people who can't get any services whatsoever because we have an extremely limited access to home and community-bases services, they're not portable, there is an eight-year waiting list and they're not available in all regions.

And I think that the number of people who are sitting there with no services whatsoever dramatically exceeds the number of people who aren't satisfied with the range of options that home and community-based services funding is allowed to cover.

MR. BADESCH: That's does and I agree with Sam, doesn't it go back to you know, when you talk about what research is needed today, you know, it's what is the best way to get someone integrative in the community? What works because what we, you know, I understand what parents, you know, I'm a parent wants to develop the programs.

But if the program they want to develop doesn't help the child or the adult or what increased their quality of life, why do it and what we're talking about here is government expenditures and policies and there's really, you know, if we're talking about everyone wanting someone integrating in the community, the more we could use research and help parents and individuals make those decisions, the better so I would be hesitant - then we could back in - how to do it.

MS. CRANE: Again, I mean, but what really got to me again and this wasn't at a presentation on a ranch that was people were living on the ranch, they were farming on the ranch and there were people at the presentation who were very upset that people couldn't use home and community-based services laborers to live on the ranch but the ranch was a licensed ICS which is only a few numbers …

((Crosstalk))

MS. CRANE: … wait a minute, I’m trying to finish my sentence - which means that you didn’t have to be on a waiting list to get into it. There were no tasks on who could use an ICS. All you have to be is a person on Medicaid. It’s harder to get a home and community-based services labor than it is to get into an ICS.

So it’s absolutely shocking that someone would take up a home and community-based labor slot to use as something that’s an ICS that everyone can get into already.

((Crosstalk))

MS. CRANE: … labor is just for people who don’t want to be in ICS and there are fewer slots for it so it’s a major barrier to people and as far as we’ve (been can’t) be talking about what we like, you know, which housing we like or thing is best without really understanding the policy and then understanding that there is a lot more funding for some things than other things.

There is a very specific dedicated funding stream for a home and community-based services but it’s smaller than the funding stream for a lot of these …

DR. KLINGER: I think part of the issue is the lack of available choices and even within these choices, the lack of available openings so for example we have an ICS program at (teach). We have an opening in our ICS program for the first time in 10 years and we’ve had more than 100 people apply for that one position.

So I think there just aren’t enough available options or available openings within the options that exist and I would have to say the biggest thing from me as a provider that keeps us from opening-up additional positions and openings is that the funding is not sufficient to cover the cost of the service.

((Crosstalk))

UNKNOWN FEMALE SPEAKER: And with those ICS I think I know the rest that you’re talking about them and they have I think 10 ICS openings and they’re granted just a few and they were asked to take those because no one else would and they are trying to do away with ICS …

MS. GOODMAN: Yes.

((Crosstalk))

UNKNOWN FEMALE SPEAKER: … other part of the argument. There’s still some (unintelligible) housing. May I make one other point too and Scott I would come back to some of the thing that you were saying, yes, we need to work on services.

My concern is if we work solely on getting the services in place and we don’t start putting together requests for research, poor medical issues and these other things so when you’re trying to do (wealth claims again) we may need to work on the strategy of doing things with our services but at the same time we need to seed research coming forward medically that can go along on a parallel track …

((Crosstalk))

UNKNOWN FEMALE SPEAKER: … the different types of research that can be done but I don’t think it has to be an either/or situation.

MR. BADESCH: I’m not suggesting and I appreciate that but I’m confused, my confusion is this is that we’re throwing a lot of stuff out there well again I think I’m trying to kind of work backwards, you know, we want every adult with autism - I would assume we’d all agree on this - they have the highest quality of life possible.

MS. GOODMAN: Best possible.

((Crosstalk))

MR. BADESCH: And then to me is what’s, you know, let’s be honest. The service system isn’t even beginning to do that so where I’m getting confused and it may just be me is that what do we need to first of all change the service systems to what it reinforces or it incentivizes people getting quality of life indicators met?

And what research do we need to have that happen so on a priority basis, if I want someone who’s 18 to have maximize his or her quality of life throughout adulthood, what’s the research I need and what I’m a little concerned about is that I mean, this is a massive issue we’re talking on a two-hour period.

You know, that we’re arguing community and grace you were arguing all these things, it just seems to me that we’re throwing a lot of stuff at and I’m having trouble and it may just be me and I apologize of how this will help my agency or help my son or help anything, best plan for service delivery so he and others we serve will maximize their quality of life.

And that’s please don’t take that as anything against research, I’m just saying and the other issue we’re having is big void that providers and I would argue parents and individuals don’t understand how to use the research so we could do research forever but I watch how decisions are made throughout the service system and rarely is someone saying let’s look at the best research to help your son or daughter or when that person’s able to make a decision, we'll base it on research.

And we're having this national discussion on community integration that it's I mean, I'm all for it but it's hard to define the research that'll show someone will be better off in a farm community or whatever when they look at quality of life measurements. I could argue why they would be if they're in a community-based. That's all I'm trying to make my point, that's the only point I'm trying to make.

((Crosstalk))

DR. DANIELS: Scott, this is Susan. I think I can clarify a little bit of that. Another point that I should have made earlier again is that this strategic plan is going to be covering both research and service delivery (unintelligible) for all of that and the purpose is for the committee to try to first clarify what the important issues are and try to bring input from the public into the discussion and then set some priorities for how we can make changes. And this advice goes back to federal agencies to all of the private organizations that sit on our committee and is something that they can think about when each of these individual agencies and organizations set their priorities and goals.

And so it is an advice-giving process, it's not an implementation process so we're not able to actually plan projects that we're ourselves going to implement but this is to try to distill the most important issues in a way that all of the stakeholders can understand and hopefully take action on.

((Crosstalk))

MR. BADESCH: Thank you Susan, I just, yes, I appreciate that.

DR. DANIELS: So yes and that’s why we really appreciate everybody being a part of this. We did want people from all across the community to have some input in this and we tried to do that through the request for public comment and having a working group of people with diverse background.

Before we close the call, the last item on my agenda was to talk about the aspirational goal for this chapter which I think does kind of bring us back to the underlying purpose for all of this.

For the committee in the past, the goal that they came-up with to describe the overall purpose of the Question 6 area and where it’s heading, I’ll read it to you is all people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships and access to necessary and individualized services and support.

Listening to the conversation it sounds like this goal would still be appropriate but I wanted to get your input about whether you feel that it’s missing anything, whether it needs to change at all.

MS. GOODMAN: Meaningful relationships …

((Crosstalk))

UNKNOWN FEMALE SPEAKER: Can you read that last maybe three lines of that?

DR. DANIELS: Sure, so all people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships and access to necessary and individualized services and support.

UNKNOWN FEMALE SPEAKER: If that has an implication to appropriate medical care for a nontypical medical population, I would say yes but I don’t know if that’s kind of embedded into that or not.

DR. TAYLOR: When I read that, I would like to think that when you talk about people with ASD having the opportunity means having their medical needs fulfilled, having their psychiatric needs fulfilled and …

((Crosstalk))

DR. TAYLOR: … I would read that as having those pieces embedded in, you know, youth are not going to have - adults are not going to have - the opportunity to do these things if they have really significant medical needs that are not being treated appropriately, right?

MS. GOODMAN: Right.

MR. PARNELL: I would agree with that and I think the wording necessary in individualized services and supports also encompasses medical and healthcare needs. I think there’s a danger in being too specific about particular areas in a general aspirational goal statement.

UNKNOWN FEMALE SPEAKER: Can I just say the necessary word that concerns me, I think people should be able to have access to more than just what’s critically necessary so I would say evidence-based and individualized.

((Crosstalk))

MS. GOODMAN: Yes, this is (Amy) and I think that somewhere in there should be something on sexuality and that …

((Crosstalk))

DR. DANIELS: So meaningful relationships probably covers that .

MS. GOODMAN: Yes.

((Crosstalk))

MS. CRANE: I’m also not sure - this is (Sam) - I’m not sure that the, I mean, the term evidence-based when we’re talking about services and support like the ones covered through Medicaid, there are some things that it’s not that they’re not evidence-based but the word can be somewhat limiting in that let’s say a person needs to come to someone’s house to help them, you know, cook their meals.

You know, that might be absolutely critically necessary but we don’t want to make it sound like we only want someone to have access to that if there is a research study saying that someone coming to your home and cooking you meal is a good thing, right?

So there’s some kinds of long-term services and supports that I think we can all agree are good but first there might not be existing research on.

MR. PARNELL: I think that’s well-put.

((Crosstalk))

UNKNOWN FEMALE SPEAKER: That’s for the non-necessary and critical.

DR. TAYLOR: What if we replaced the necessary with needed, access to needed and individualized services because I agree that you don’t want that to be limiting by somebody reading the statement and saying well, I don’t determine that that’s necessary or …

((Crosstalk))

DR. DANIELS: What about word appropriate.

UNKNOWN FEMALE SPEAKER: Appropriate, uh huh.

UNKNOWN FEMALE SPEAKER:Yes, appropriate sounds …

((Crosstalk))

DR. TAYLOR: Yes, I like that.

((Crosstalk))

DR. DANIELS: So we could replace that word. (Susan) just from my perspective here in the government I think evidence-based is something that could be interpreted as limiting to services that are based on research studies and so you might not want to get that narrow so that's great and then for the chapter title what does the future hold particularly for adults, do people still feel comfortable with that chapter title as this whole area has really evolved over the last few years. Does that still capture where we thing that this is going?

((Crosstalk))

MS. CRANE: It's future, right, some people's the (unintelligible) …

DR. TAYLOR: What is we and I also think we've got some data on, I think our questions are a lot bigger than just understanding what the future holds so I wonder if we want to change it to more of a focus on like how do we help as well as with ASC achieve their highest potential or something to that effect?

Then it encompasses the services, research, you know, the descriptive study's put into that too, I feel like that encompassed a broad range of ideas that we're talking about in the report.

DR. DANIELS: So I think you all can have some more time to thank about this. Maybe I'll come back to that next time but be thinking about that. I just wrote down what (Julie) said and if maybe we could put that out as a straw man and next time if people come with some ideas about how you might want to adjust the title, if you think that it needs to be adjusted.

MS. GOODMAN: Yes, yes.

DR. DANIELS: So given that we are a couple minutes past the hour, I want to be able to wrap us up. On the next call we're going to be talking about three objectives that we can set for this question area and these objectives can be very broad.

They can encompass both research and services as well as policy but general goals that you would have for the whole area related to adulthood, transition to adulthood, etcetera, and so we can take some suggestions for this via e-mail ahead of time and then we'll be talking about it on the call and trying to distill it down to just three so that we'll end-up with 20 or 21 objectives for the entire strategic plan.

So we'll be talking more about that next time. Really appreciate everyone's input into all the topics and we'll be in touch with more information about the next call and your writing task.

I'll be working with the chairs to do an outline of this chapter and then the chairs will be helping to recruit various members to help write or edit different sections and of course all of the working groups will have a chance to see what's being put together so thank you all for your time. Are there any questions before we adjourn?

((Crosstalk))

UNKNOWN FEMALE SPEAKER: You do a good job, (Susan), thank you.

DR. DANIELS: Thank you.

MS. GOODMAN: No, thank you.

((Crosstalk))

DR. DANIELS: Thanks so much for participating and we look forward to talking to you next time.

(Whereupon, the conference call was adjourned.)