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INTERAGENCY AUTISM COORDINATING COMMITTEE

STRATEGIC PLAN UPDATE

Working Group 5 – Question 5 – Where Can I Turn for Services?

Conference Call 2

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Proceedings:

DR. SUSAN DANIELS: Thank you. Hi. This is Dr. Susan Daniels at the National Institutes of Health Office of Autism Research Coordination within the National Institute of Mental Health welcoming you to today's phone call. Of the - the conference call will be IACC strategic plan update working group for question five, where can I turn for services, which is a part of the IACC strategic plan.

Welcome to our public audience who is listening on the phone. All the materials are online on the IACC Web site so you can go there to find materials so you can follow along. And welcome to our working group members into co-chair, Shannon Haworth, today who's also on the call. I'm going to just do a brief roll call so that people who are listening on the phone will know who is on the phone. And we did introductions last time some just going to do a simple roll call and then we'll move right into the agenda. So, Shannon Haworth.

MS. SHANNON HAWORTH: Yes, I'm here.

DR. DANIELS: Thank you. David Mandell is not going to be able to join us today. Samantha Crane.

MS. SAMANTHA CRANE: Yes.

DR. DANIELS: Thanks. Melissa Harris.

DR. MELISSA HARRIS: I'm here.

DR. DANIELS: Laura Kavanagh? Brian Parnell? Larry Wexler?

DR. LARRY WEXLER: Yes.

DR. DANIELS: Hi. Lauren Brookman-Frazee?

DR. LAUREN BROOKMAN-FRAZEE: I'm here.

DR. DANIELS: Thanks. Robert Cimera?

DR. ROBERT CIMERA: I'm here.

DR. DANIELS: Daniel Davis?

MR. DANIEL DAVIS: I'm here.

DR. DANIELS: Thanks. Peter Gerhardt? Lisa Goring? Leticia Manning?

MS. LETICIA MANNING: Present.

DR. DANIELS: Thanks. Cathy Pratt?

DR. CATHY PRATT: Here.

DR. DANIELS: Ann Roux is not going to be able to join us today. Aubyn Stahmer?

DR. AUBYN STAHMER: I'm here.

DR. DANIELS: Jane Tilly?

MS. JANE TILLY: Here.

DR. DANIELS: And Juliann Woods?

DR. JULIANN WOODS: I'm here, too. Thank you.

DR. DANIELS: Thank you. Great to have you on the call. Reminding everyone who's listening in on the phone and might not have been on the earlier call that we had last week that Ms. Shannon Haworth and David Mandell, who are both members of the IACC are the co-chairs of this group.

And to briefly follow-up from our call this week, we have published the transcript online. It's on our Web site where we have the materials for the different working groups. So if you go to call one and go down to the bottom of the page, you can find the transcript if you need it. And we are preparing a set of notes for the working group but I haven’t had a chance had to send out all of the notes.

So we will make sure that you have them before you start your writing task. So the first item that we have on our agenda today is to take some time to discuss the public comments that we received through a request for public information - or a request for information from the public that we put out on the IACC Web site over the summer. And so we put out a call for public comment on the various chapters of the strategic plan on those topic areas to see what were important issues that the public wanted to highlight for attention in the new strategic plan.

And we have put those comments online on our Web site so if you go to the section that’s on public comments in the meeting section or from the homepage carousel, there’s also a link. You can go right into the full text comments. But to help this working group and the committee with this task, my team here in the Office of Autism Research Coordination tried to distill out some of the major themes that came up in the public comments that were received.

And so we provided this in one of the documents that was in your materials so it’s called the list of themes from the request for public comment on IACC 2016 strategic plan for ASD. So the different teams that came up were early intervention services which is the subject that’s now going to be moved to question one, so that’s something that this group will not necessarily need to delve into angry detail.

Disparities in access and services, family well-being, efficacious and cost-effective services, educational services, service systems and delivery, access to services, quart mason choice and relevant services, qualified workforce, community inclusion, specific ASD services, assistance and navigating services, health and safety, community education, cost of services. Some comments that said that the current priorities in the strategic plan or appropriate. And focus on treatment and cause rather than delivery of services which was really for question three.

So that also is something that this group doesn't necessarily need to address. For those of you that have the opportunity to browse the comments, would you like to share in every thoughts about comments or important themes that were shared by the public?

(Long pause.)

MS. HAWORTH: Hi. This is Shannon Haworth.

DR. DANIELS: Hi, Shannon.

MS. HAWORTH: Hi. I didn't see a lot about, like, pediatric to adult-based care or treatment and care throughout the lifespan because there's a focus - I know we're not going to talk about early intervention but there's a focus on youth, but not so much as the agent how treatments and the services will change with them.

DR. DANIELS: So that topic is likely in question six because that's the lifespan chapter.

MS. HAWORTH: Okay.

DR. DANIELS: Those types of comments went there. So that's probably why you didn't see it, although obviously the issue of lifespan with respect to services is important.

MS. CRANE: This is Sam. I'm sort of interested in the comments about the services workforce and was wondering, is there - I mean, should that actually be in question seven because it somewhat of an infrastructure issue versus, you know, research on, you know, which services work and which services, you know, produce a good outcomes, would count as research but workforce development sounds like question seven to me.

DR. DANIELS: So in - historically in question seven, the only workforce issues that were covered there were research workforce and services workforce wasn’t specifically covered. And so now that the strategic plan chapters are each going to have a section on research and a section on service delivery, the service practitioner workforce will be covered in that services section and the services chapter.

MS. CRANE: Okay. Okay, that makes sense. That makes sense.

DR. DANIELS: Okay, so that’s something that’s fair game especially you all are more of the experts in that area so that I think it to be appropriate for you to be able to work on that in your chapter.

MS. CRANE: So that will be - federal end up in question seven this time around.

DR. DANIELS: No, it’ll end up in question five. So it will be the second half of question five, so I didn’t give it to specifically with your packets this time but last time we talked about the structure of the strategic plan update when we discussed the overview of progress in the field, there will be two large sections. One that’ll be a research update, just about - so in this case it a be about services research and what’s been happening and services research. And then there’ll be a services policy update where you can talk about programs and policy.

And so workforce issues will be covered in that section for every chapter. So, for example, in question one, the screening and diagnosis service practitioners will be covered there if they have particular issues that they need to talk about in terms of workforce. And so for services workforce needs, this group will be able to address that in that second half of the progress section.

MS. CRANE: What I mean actually, though, is, you know, things like the Lend program which had a research component but it was sort of studying, you know, which kinds of ways are, you know, best to train services professionals, I think that it’s really important to at least have some way to divide that away from research on which services are actually effective and which services, you know, the outcomes of those services.

And, you know, I’m not sure whether it should go in question seven because it’s research on how to expand services or if maybe they can just - we need to just make them part of a separate objective within question five. Or - because it doesn’t sound to me like it’s in the policy - it would be the policy aspect of question five because they are research studies.

DR. DANIELS: So for the strategic plan, the law had suggested that we needed to expand the plan to include more about services and support. And so throughout the entire plan every chapter is going to have sections about services and supports even related to research areas.

MS. CRANE: Okay.

DR. DANIELS: So the structure that we were planning on was for there to be a services policy section for each of the different chapters. So for question five, we would have that and so workforce would fit in there. They could be put in chapter seven but I think it would probably make more sense to put it in this chapter because you’re going to be talking about all the different services issues and I think the needs for the services workforce will naturally flow out of that.

And so will probably the more of a logical flow for it to be a part of this chapter. This is totally separate from the portfolio analysis. The portfolio analysis still remains research. It’s not focused on service delivery. So in terms of the measurement for the portfolio analysis, that will remain research. So I don’t know that clarifies that for you.

MS. CRANE: I’m not entirely sure but I’ll wait until later and try to talk to…

DR. DANIELS: And when the chairs work on the island for the chapter, if, after this discussion, they feel strongly that you don’t - this group does not want to address workforce issues for the services workforce, we could discuss whether he needs to be moved elsewhere. But it seemed like this group would have expertise to talk about those needs. Any other thoughts about some of the specific concerns that members of the public had or some of these themes and, you know, your thoughts about them?

(No response.)

DR. DANIELS: So we also will be sharing the public comments but the committee on our October 6th - 26th IACC meeting and so the committee will also have a chance to discuss what came in on public comment. But we wanted to be sure that these public comments are conveyed to both the working group and the committees so that you could take them into account when writing. So it sounds like there aren’t any comments on the public comment period.

UNKNOWN FEMALE SPEAKER: Susan, let me just reiterate a comment from last time. I think, you know, Paul Shattuck’s work shows us that, about 60% of our folks have co-occurring health and mental health stuff. So I hope that we don’t forget about those individuals who present with some of the most complex challenges.

DR. DANIELS: Okay.

DR. STAHMER: I wonder if that fits in coordination, choice and relevant services. This is Aubyn.

DR. DANIELS: I don’t think it’s a specific theme that our team picked up on as a theme, although it may be in the comments and so we can go back and look at even just a lot of comments that had to do with that. There have been discussions in the IACC about ensuring the needs of the most severely affected members of the community are addressed. And so I think that’s kind of in line with what you’re discussing.

Anything else to note on this before we move on?

(No response.)

DR. DANIELS: All right, so then let’s move on to the next section of our agenda which is the discussion of research progress. So this will be the first task of that overview of progress section that this working group is going to be drafting for the strategic plan update. And so I wanted to just provide you with some questions to give you an opportunity to respond and share from your own experiences and expertise about things that you think are major priorities that should be mentioned in the strategic plan update.

So to start with the first question on the discussion question list, what are the most notable areas of recent progress in this question field of research and what new opportunities have emerged? So, anyone have thoughts on that?

(No response.)

DR. DANIELS: Important changes that have happened in the field in the last couple of years?

DR. STAHMER: This is Aubyn. On our last call, I feel like we talked - the last time, but the last time we did this review - we talked a lot about the fact that we understood now a lot about the disparities in the barriers to service and there wasn't a lot of research going on about what to do about those barriers.

It seems like now the portfolio, or at least the research that's happening that may be hasn't even gotten to the portfolio yet, is, more people are looking at how to actually address those spheres. And I think that that is a really important new area that needs to keep moving forward but I feel like we've got a better start than we did at her last review.

DR. DANIELS: To have any examples that you want to share?

DR. STAHMER: Well, I'm thinking that HRSA studies the (air V) - I feel a little weird because I don't want to just say things I'm on. But somebody mentioned London and I think that that has moved more toward disparities, the access grants. So I just feel like it's been moving toward how to get families who are traditionally under resource into services.

MS. HAWORTH: Hi, Susan. This is Shannon.

DR. DANIELS: Yes.

MS. HAYWORTH: I think a lot of the gaps in services have been identified, both of the work through Paul Shattuck and Drexel, as well as the GAO report that will be coming out shortly. So I think that's a step in the right direction and with the services with the gaps but also the need for services throughout the lifespan.

DR. DANIELS: Yes, and with the GAO report that still pending, that's something that, once it's published, the working group can look at with respect to this question if there are parts of it that are relevant.

MS. CRANE: This is Sam. I think the research on employment services has also been really useful. For example, the Paul Lehman study on facilitated employment for use, use the internship models, and that's the kind of research that we would love to see more of. It's just sort of basic efficacy - you know, let's see about how we can test efficacy of different long-term services programs.

(Long pause.)

MS. CRANE: Especially ones that are more and more integrated.

DR. DANIELS: So I did share with you all a list of topics for question five and maybe I should go back to that quickly to go over some of the things that were captured that were part of question five last time around and/or have come up in discussion with the committee and see if have thoughts about some of those. Now, I know that employment as a whole will probably be covered in question six as related to adults.

But some of the areas that are here and want to hear if you think there are things that have been missed or that are also priorities that should be put on this list, are, first, the services research portion, research and services approaches for children on the autism spectrum because the adults section will be covered in question six. Healthcare service disparities, which we've been talking about. Research and service quality, effectiveness, delivery and implementation, studies of services utilization and access which probably will span both this chapter in the next.

Comparative effectiveness research, economics research, family well-being and safety, caregiver support, development and evaluation of practitioner training, evaluation of services models, evaluation of impacts of state and federal policies including services, education. Transition will be in question six but some of those types of policies. Development of technology based services and research on person centered self-directed services and support. So that was one list. Furthermore services research topics that you think are important or do you have more to say about some of the ones I just read off?

MS. CRANE: So this is Sam. The employment research I was talking about was actually for use. It was people under the age of 18, I think, so I would disagree that transition, you know, transition is a tricky topic. But it's - I worry about watering down - you know, there's already very little research on the needs of adults. And if we sort of automatically put all transition oriented stuff into the adults questions, even when it's focused on people under the age of 18, I'm worried about watering it down even more.

And then I wanted to sort of reiterate my comments from last time that I think when we talk about the topics, we really want to make sure that we have a way to separate out, you know, research on long-term services and support and, you know, ancillary services like healthcare from things like economics research or practitioner training because it just really helps the advocacy community keep track of how much is spent on each topic - subtopic.

DR. DANIELS: So in terms of transition, we've been covering it in chapter 6 now for many years and so I don't think that the committee is probably going to want to change it at this point because it would kind of change the tracking so that it would be hard to change over time. So transition is currently covered in chapter six and so unless the committee changes that, it still will be in the future.

MS. CRANE: And why was it counted under chapter question five? I’m looking at the, like, list of studies and the one that I mentioned was in question five.

DR. DANIELS: So I would have to look back at that to see, but in general, the transition has been covered in question six.

MS. CRANE: Yes. I just don’t want to move it anywhere because it’s right now in question, you know, it was counted in question five, so I’m guessing that it was because it was for youth and not adults.

DR. DANIELS: It might be. We would have to look back at it to see if there was a particular reason that it was there. But the bolus of transition is in question six.

DR. WEXLER: Hey, Susan, this is Larry. Can you hear me?

DR. DANIELS: Mm-hmm.

DR. WEXLER: Yes, well, one of the things that the other end of the spectrum from (Sam) that we might want to consider is we’ve been dealing with an ongoing policy issue around removal of young children from educational environments because of their behavior. And my guess is that a lot of kids with ASD are in that category and so, you know, additional focus on behavioral interventions that would prevent removal and removal from the instructional or - will call it instructional - from the instructional environment.

If they’re not in a learning environment, it’s unlikely that going to be benefiting from instruction.

MS. CRANE: The question I would have is, how do we decide what counts as an early intervention or intervention in general and how much - how do we decide what's a service?

DR. DANIELS: So in this chapter he mostly discuss implementation type of studies. So if it's experimental, like early development of an intervention, that's in question four. But I think that what Larry speaks to us need. And I think that the second portion of this chapter that talks about services and policy and the needs of the community could cover that and that actual interventions that are being developed would be in question four. But the discussion of the need could be here.

MS. CRANE: But it's like, we developed a behavioral intervention and we're trying to see if it helps event people from being taken out of mainstream classrooms and they're evaluating the outcome, with that instead be - with that so the question five?

DR. DANIELS: If they're in the classroom setting or in the community setting, then it would be in question five. We're really not discussing the research portfolio so much today. We're really talking about advances that have been made in research on services and so we wanted to get some of your thoughts on major ways the field has moved forward. Or if you feel that there are a lot of gaps, a lot of areas where the fields have not been moving forward, what are the barriers that have been preventing it from moving forward and maybe need to be addressed?

DR. PRATT: Susan, this Cathy Pratt. I think, for me, I like these categories, and Laura, I appreciate your comments. But I think for me, we've learned a lot from (Dean Vixon)'s work about implementation science and scaling up. And I know I was involved in Sam Odom's products who is a national professional development center. And I have to tell you the way that he framed that work probably had the greatest impact on our state, and the work that’s been done through the grants that have been funded.

And I would just remind people that not everyone lives in the hub of a university our research institution and so I think always be mindful of the fact that we have to make sure that we’re scaling this stuff up and that we’re really talking about implementation science.

DR. DANIELS: So Cathy, what are some of the barriers to being able to do that effectively?

DR. PRATT: Well, I think, you know, you have to understand kind of the culture that you’re working in. I think, again, with Sam’s work around the national professional development center, he had standards and he had a guide and he had fidelity implementation checklists.

And there is very clear research and processes that people went through. And for us, there was also some flexibility in terms of how we did that so that we could - because I’m kind of - I kind of shy away from the concept of a model program because I think that every - I work in a lot of schools that you have to be responsive to the culture of the schools.

But I think instead, we have to think about demonstration (sites), you know, how we create sites that people can go in and look at. And in our state, through (Sam)’s work, we’ve been able to create a number of demonstration sites that then people in our state can go in and look at.

And we can do more peer-to-peer coaching so the principals can talk to other principals. The general education teachers can talk to other general education folks and so I think really doing work that is very rich in the field is really important.

DR. DANIELS: So do those opportunities exist across the United States? Are they still very limited or are they expanding?

DR. PRATT: I think that there are, in different states, infrastructures for doing that. I know that through the AUCD network, we try to stay connected about how we enrich each other’s programs and services. There are number of us to get together who run statewide programs and we have the infrastructures. My program is not going to go away. My program is not dependent on a year-to-year grant.

And we have been building an infrastructure and our state for years. So I think being able to go in to a state and look to see what systems are in place that can really look at that implementation science.

DR. WOODS: Hi, everyone. This is Juliann and I want to follow-up and thank Cathy for opening this conversation. One of the things that I’ve been thinking about, and I’m sure Larry’s going to help out with this conversation, is that our state’s education systems are undergoing plans that are long-term and using implementation science.

And I think our ability to use or to infuse (unintelligible) initiatives into those state plans could really have really good progress and then it would be available everywhere. Each state will have to look at their own unique circumstances but it would bring this to the forefront and allow for, not only systematic implementation, but a really great evaluation because the state plans include evaluative components.

So I don’t know if I opened the door for you, Larry, and you wanted to jump in or not, but I think that coordinating with some of the projects that are there that are going to be ongoing, as Cathy mentioned, can really facilitate moving the research to practice so much faster and more consistently.

DR. WEXLER: I think you said it better than me.

DR. PRATT: Well, I think, Susan, that keeping those of us who are doing this work statewide, I mean, I cover the entire state of Indiana and my staff and I, and so while we're going and not initiatives around autism, we also talk about, in schools for example, how we go through the door of autism that we strengthen the entire school culture.

And so I think all of us have to look at a broader picture and how we infused this work within that broader picture. But I think then connecting those of us who are doing the statewide work is really critical because I think that we understand the variables in our state and can kind of help to maneuver through some of those.

DR. DANIELS: Great. Thanks. Others have comments on some of this?

MS. CRANE: Yes, this is Sam again. I think, you know, one of the things that we're really concerned about is - and the reason why we're - we keep sort of asking if we can separate a lot of these different kinds of question, five topics, out is we're saying really, really limited progress in terms of developing things that we would call supports more than interventions.

And that would include sort of long-term services and supports rather than things like behavioral therapies or interventions. We also are - think that there needs to be a bit more of a focus on communication support and services. So access to a (fee devices), access to communication support, especially for people on the autism spectrum for nonspeaking. I'm not sure where else that could do except for in this question.

DR. DANIELS: That’s not appropriate for this question. I think that was what was referred to in developmental technology based services, was talking about different types of a system communication and other technologies that would be helpful. And that can be a broad…

MS. CRANE: Yes, and there’re a lot of different other kinds of technology based services as well.

DR. DANIELS: Right. Do you want to comment on any of those?

MS. CRANE: No, I mean, I just wanted to say that, you know, sometimes when we look at a category that’s technology in general, it doesn’t necessarily specify what the technology is being used for. And we would want to sort of separate out communication a little bit. And partly because not all communication services are tech-based. Not all communication support are tech-based so we would want to sort of see we can lump them together.

DR. DANIELS: Other thoughts on anything that’s been discussed so far? (Robert), do you have anything to share about economics research and where we are with that, what’s happened recently and what are some remaining needs?

DR. CIMERA: I don’t know if you want me to talk about economics research. I get kind of excited about it so I made for you all.

DR. DANIELS: That’s why we invited you.

DR. CIMERA: I think we’re making strides in economic research. The difficulty that we have with any kind of economic research on any disability is that economics changes so frequently. So instead of seeing this as - it needs to be an ongoing line of inquiry because things change economically throughout the country as well as regionally.

Some of the things I think we need to expand upon in the field is looking at economic outcomes of individuals with autism as well as cost of services in rural areas, for example, or areas that are not supported immediately by a university as summary had said. There’s a whole bunch of different avenues to look at the economic research. There’s just - it hasn’t been that much attention given to it, though, recently.

DR. DANIELS: Are there any particular barriers that are preventing or from being done?

DR. CIMERA: Part of it getting data, you know, that - I utilize a lot of VR databases but there’s a lot of other data that could be out there that we could be looking at. So if there’s a program that a state or an agency has implemented, it’s really interesting to look at whether those services that they’re providing actually result in less costly, more efficient services and that’s kind of my area that I enjoy looking at. It’s just a matter of getting data from people because no one wants to share issues with money. It’s a very sensitive topic.

DR. DANIELS: Do you have any suggestions about things that could be done to alleviate that?

DR. CIMERA: Well, it would be nice to have more national databases but that’s not going to happen overnight. You know, VR certainly has their databases. It would be nice to have some sort of - when people get grants, have a recording mechanism for those kinds of issues.

The problem is, it’s a very specialized talent to identify costs because you have to identify costs in relationship to something. It’s not just what you spend. It’s what you stand in relation to somebody or a service on outcome.

So frequently when I work with states collect the data and costs, to collect the wrong information and information that cannot be utilized in the research way. So there's a lot we can discuss. I just don't know how much detail you want to go into.

DR. DANIELS: So I think with question seven, they might be able to - maybe I can have you interact with them a little bit about that because they are going to be discussing a lot about collections of data and ensuring that researchers have access to data. So maybe more of the detail could go there.

DR. CIMERA: Oh, that would be wonderful.

DR. DANIELS: Yes, that's an important issue as well. Does - do any of the agencies that are on the call have anything to share about what they have been recently doing that has contributed to this area?

((Crosstalk))

DR. DANIELS: I know that Larry Wexler I spoke a little bit about the Department of Ed, but anybody else?

MR. DAVIS: Well, I would - this is Daniel Davis. At ACL I think we have been starting to look at issues were generally around access to services when it comes to ACL's work.

We've definitely been taking an interest in, you know, in identifying measures that determine whether people are getting to the providers, they're supposed be seeing and then, you know, that there are a sufficient supply of providers that are being covered. I think that that's something that we're definitely taking a closer look at.

DR. DANIELS: Have we learned anything recently that has changed where that research is going?

MR. DAVIS: Well, at this point, I think we're - I think the main thing that has changed, that is that CMS has issued a final rule and then a request for information on access to care. It's more broadly than just - than anyone particular condition, but it does certainly set some of the parameters by which access to care is being tracked under Medicaid state plant services.

And we do believe that, over time, is going to have some influence on the conversation. Relatedly, there are, you know, whole new sets of rules around network adequacy that have gone into effect under Medicaid managed care and under - and come of course, little bit further, a little bit longer ago, under Affordable Care Act which also comes into play. So I think at this point it's a bit too early to tell other than to know that we're dealing in somewhat of a new landscape and that the relevant regulators are still, in many cases, looking to identify the correct metrics for measuring access to care.

MS. MELISSA HARRIS: And, Susan, this is Melissa Harris with CMS and, you know, to - Daniel's exactly correct and I'll talk a little bit more about the Medicaid perspective in terms of both the coverage of services and then access to them. A couple of years ago, the summer of 2014, CMS issued guidance to all of our state Medicaid agency partners and really all of our stakeholders indicating that services to treat a Medicaid eligible child who has a diagnosis of an autism spectrum disorder is part of a state's responsibilities under Medicaid's EPST mandate.

EPST standing for Early and Periodic Screening Diagnostic and Testing benefits which says that for a Medicaid beneficiary under the age of 21, any medically necessary service to correct or ameliorate a condition that's authorized in

Section 1905(a) as in Adam of the Social Security Act needs to be provided to children, whether or not such services are furnished to adults over the age of 21.

And if you look at 1905(a), the Social Security Act, there's a lot of very broad coverage categories like physician, inpatient hospital, clinic services provided by other licensed practitioners, preventive services and states had really been in the driver seat at determining the discreet interventions that would be covered under those coverage categories.

And both states and CMS historically had looked at services that were really teaching new skills and new behaviors, as kind of separate and apart from that list of services in that part of the statute. We’d called them habilitative services as contrasted with rehabilitative services, which were covered under that part of the Medicaid menu. And states had largely offered those habilitative treatments or, you know, learning new skills or new behaviors.

States had merely covered them in (waiver) programs where they could limit the number of individuals served and had a cost cap of services – or the amount of services that the state would have expended to treat that individual in an institution. What our guidance in 2014 said was that states could not any longer limit the provision of services to treat the autism disorder to just those authorized under waivers and states had to cover the interventions designed to treat the child’s autism disorder as part of its EPST mandate.

It didn’t require states to provide a specific type of therapy - some kind of misinterpreted our bulletin as requiring states to provide a planned behavioral analysis. And it’s really not what we said.

So states are still the determiner of what kinds of autism treatment to provide, but they have to be providing services to treat the underlying autism condition under EPST.

Even though that guidance was released two years ago, states are in different places in terms of implementing the guidance and we still sometimes hear of states who are not quite there in terms of having services available statewide by a robust provider network to treat children with an autism disorder. And states still do need to be mindful of the individualized treatment requirement that’s really at the heart of EPST. So an autism service that is medically appropriate for one child, may not be medically appropriate for the next child and states really do need to bring that kind of individualized approach to service authorization.

So I wanted to make sure that people understood the context of the availability of Medicaid funding of autism services. But that’s really only part of the conversation. You know now that we’ve kind of removed the barrier to services being federally available for Medicaid dollars, the next part of the equation is making sure that there are actually providers on the ground to deliver those services. And that’s where the access conversation comes in and Daniel’s right that we did issue a final regulation on access across the Medicaid program. It took effective the beginning of this calendar year and really focuses on actions that a state Medicaid agency might take to reduce payment to providers.

So whenever a state puts an action in front of CMS to lower the payment rate provided to Medicaid providers of service, the state needs to do an analysis of what the expected impacts are going to be on provider participation in Medicaid as a result of those payment reductions. And a lot of the service categories that services for an autism diagnosis would be covered under are part of those access analysis that a state would need to do.

As Daniel also mentioned, there is a request for information that a company in the publication of the final rule that really sought to keep the conversation going and solicited public input on more robust ways to measure access, particularly to home and community-based services, and would - that are much harder to determine how to measure than the more primary and acute and preventive services, and we are analyzing the responses to that.

So it is very much an ongoing conversation besides the analysis the state needs to do when they are reducing payment rates, they also need to submit to us a access monitoring plan every three years that kind of paints a picture of how access is going across their Medicaid services. No state has had to do that yet because the regulation was just in effect the beginning of this last calendar year, so suffice it to say that this is very much a work in progress.

But we are keenly focused on how the reimbursement structure and Medicaid impacts provider participation, and how that obviously impacts the ability of individuals to receive services that they've been determined to medically necessary to receive. That's a long conversation and I apologize for usurping a lot of the dialogue but did was give some context to what's been happening in the Medicaid context. Thanks.

DR. DANIELS: We appreciate it, thank you. That was a nice summary of some of the recent progress and it'll be important to capture that in the chapter when it's written. Other with updates?

(No response.)

DR. DANIELS: So there were some major themes even among these different topics that were in the list of topics and I’m not sure if we’ve touched on all of them. Does anyone have comments about recent progress that's been made in self-direction and person-centered services and supports?

MS. CRANE: This is Sam again and I’m now really confused about why that’s not in Question 6.

DR. DANIELS: That will probably be repeated in Question 6 to some extent, but it had been a topic here because it also applies to children.

MS. CRANE: Yes, so we’ve been – maybe Melissa would be the best person to talk about this, but I think that the home and community-based settings rule is actually going to be really relevant to that. If she doesn’t want to, I can go and say what it is.

MS. HARRIS: I’m happy to start out Sam and then you can talk – you can piggyback on…

MS. CRANE: Yes.

MS. HARRIS: So we’ve been fairly busy at CMS the last couple of years. Also, in 2014 we issued a final regulation in January with an expected date in March. Defining what a home and community-based setting is as it relates to funding for home and community-based services offered under three discreet Medicaid authorities.

You all might be familiar with home and community-based waivers that have been part of the Medicaid landscape for well over 30 years. There are also a couple of other HCBS authorities that require services to be provided in a home and community-based setting, and before this regulation there was no standard definition of what that meant.

And what we were finding in our own on the ground research and based on what we were hearing from other stakeholders is that there were a lot of HCBS funding going to services provided in locations that really were tough to distinguish from an institution – like a nursing facility, an intermediate care facility for individuals with intellectual or developmental disabilities.

And so the purpose of the regulation is to talk about the community integration requirements that are really at the heart of a setting that is truly home and community based. It does not take a one-size-fits-all approach because that's a total fallacy and really anything to do with healthcare, but does lay out some standard expectations that a setting providing either residential services or day services under the (rule brick) of home and community-based services needs to meet.

And there are things like facilitating a beneficiary’s integration into the community based on what their goals and preferences are, what kind of support they would need during the day. Are they focused on pursuing employment or are they doing some other kind of activity during the day?

Residentially as their provider facilitating them experiencing the community the way the rest of us experience the community. With the ability for the person-centered care plan to be really the driving force behind articulating how that individual wants to be experiencing the community, and to any kind of modifications or restrictions on that community integration, that need to be talked about because of the individual’s healthcare conditions.

So we are in a transition period that started when the final regulation was published and runs through March of 2019 in which federal dollars are still flowing to all settings that right now are providing services labelled as HCBS. But the transition period is designed to give states and their providers and all of their stakeholders all the way down to and especially including Medicaid beneficiaries and their families, the opportunity to figure out how best to get a state’s administrative infrastructure in place.

And also working with their providers to make sure that provider operations are in line with the settings requirement. It also lays out a couple of descriptions of settings that are going to be presumed to have institutional characteristics because of either their location or the way they have structured their operations.

It does not prevent those settings from ultimately being adjudicated to be home and community-based but it does mean that the state will need to do a special analysis of those settings and then send documentation to CMS kind of validating the fact that that setting really does meet the requirements of a home and community-based setting. You know, I could talk for a long time on this and don’t want to usurp the call and (Sam) jump in.

DR. DANIELS: And Melissa this is the part that is going to be in Question 6, so we probably don’t want to spend a huge amount of time on it on this call but definitely the information that you’ve shared should be useful to the Question 6 group and they can use it when they are talking about that topic.

MS. CRANE: But – so the reason – this is Sam – the reason why I brought it up is that, you know, there are children on HCBS waivers, and all of those children will now have to be getting person-centered planning…

DR. DANIELS: Okay.

MS. CRANE: …in order to get services through those waivers. So that's why I asked first, you know, why is this not in Question 6 and then, you know, when you said we’ll be thinking of long term services and supports for children as well, that's why I brought it up that the person-centered planning requirements are cross-age group and are going to be really useful for the population of children that might otherwise be facing segregation or placement in institutional settings like residential treatment centers.

DR. DANIELS: Thanks for that clarification. Anything else about person-centered planning or self-direction research or implementation?

(No response.)

DR. DANIELS: So other themes that had come up in the past were coordination across agencies, of services and how we think we're doing with that, or what has changed in the last few years with regard to that and what are the remaining needs?

(Long pause.)

DR. DANIELS: All right, quality, so…

DR. BROOKMAN-FRAZEE: This is Lauren. I want to make a comment on the last question about the multiple services.

DR. DANIELS: Sure.

DR. BROOKMAN-FRAZEE: I think there's the progress that there is growing awareness that individuals with autism are served in multiple service systems, but I think that maybe the direction – one future direction is the navigation between these service systems, either at the same time or, you know, over time.

And I think that that – it relates to – some of the conversations about transition but it also related to access because there are the transitions between service systems have a potential to be where we lose folks. So I think that, again, there is greater awareness of multiple service system involvement but room for future research on families navigating through the system.

MS. HAWORTH: Hi Susan this is Shannon, I just wanted to bring up – I know there's a lot of research on medical homes and how medical homes help families to coordinate and navigate services as well. So that might be something important to look at.

DR. DANIELS: Yes, so can you comment a little bit more about what's been happening with that.

MS. HAWORTH: Well, I mean, I haven't seen in practiced a lot, but I've seen a lot of research about the importance of medical homes and getting the federal definition versus the functional definition of what a medical home really is.

I mean I've seen it work, but they're not a lot – the implementation, you know, needs a lot of work as well, but it will help families to just have that central – that central source or that central place where they know all their providers and all their services are being coordinated, whether it be their PCP office or, you know, psychiatry or (psychology) (unintelligible) that one place that they know that their services are being coordinated. It's been very helpful to families, but I really haven't seen it in action a lot. But I do see continued research.

DR. DANIELS: Anyone else have any comments about medical home concepts? Another theme that you have mentioned a little bit here on the call today but could be elaborated upon is disparities. And any specific examples of progress we've made in the area of disparities and remaining gaps that we need to address and that the committee may want to address through the strategic plan update?

(Long pause.)

MS. MANNING: This is Leticia from HRSA and I’m not sure about the research in this area but I do know that we have tried to make disparities an important component of some of our newer grant programs, and I think it’s important to acknowledge that there’s not only disparities within race and ethnicity, but also in location.

So rural versus urban and vice versa – I don’t know if there have been tremendous strides made in this area in particular. But I do think there are some initiatives that are attempting to look at the issue and address it.

DR. DANIELS: Something that has come up in the committee is that – is the concept of thinking about people with disabilities as a disparity group or under-served group as a whole, and I don’t know if the working group has thoughts on that and anything that may be included in the strategic plan about considering disparities that affect people’s disabilities such as autism.

MR. DAVIS: Hi this is – I’m sorry – yes, this is Daniel from ACL. We’ve definitely been tracking a number of those developments related to disparities. We definitely think that the body of the evidence is becoming significantly more substantive in terms of disability, in terms of showing disabilities disparities than had existed before.

I think a lot more data has begun to come to light. We know that in fact (Niddler) is in fact funding a significant amount of research that looks into Affordable Care Act Implementation but also potentially disparities between people with disabilities and people without disabilities as far as implementation. So that's definitely been something we’re looking at. We are also, you know, tracking the proposed revisions to the (NHIS) National Health Interview Survey because those may well have some bearing in terms of identifying and addressing needs of people with developmental disabilities.

We’ve definitely heard some comments and concerns there raising questions about what other surveys beyond and has also identified age of onsets for developmental disabilities and I think that potentially an area of significant attention going forward.

DR. DANIELS: Thanks. Other comments on that.

MS. HAWORTH: This is Shannon, I just wanted to thank Daniel for bringing that up. And as well I know the (ACL) network has looked at having disability being pushing forward to be designated as a despaired or under-served population and tying that to loan forgiveness to possibly opening up more providers being interested in serving people with disabilities.

And I also wanted to bring up – I don’t know if it was talked about, but Tele-health from someone brought up about rural areas and services. There’s a lot of research on Tele-health services, especially like behavioral health services. Maybe that's something we can discuss.

MS. HAWORTH: NIH does have some grants in that area and probably some other agencies do as well.

DR. STAHMER: This is Aubyn and I think that expanding Tele-health and distance learning, both for service delivery and for training I think are both important areas for technology.

DR. WOODS: This is Juliann and I agree with that and while there is research, I’m not sure it’s getting at service utilization and particularly with our little one – is is being that services is being – and how effectively is it being utilized when there is multiple services available.

DR. PRATT: I know – this is Cathy – I know that in Indiana, again related to our folks who have co-occurring disorders – we’re really looking at the systems of care model.

You know we used to talk about wrap-around services, but what I find is that individuals don’t fit into neat categories of funding streams and how to kind of merge resources when individuals have multiple and complex needs.

DR. DANIELS: Other comments on those? There’s something that the committee had asked us to try to cover throughout this strategic plan was the loop from practice to research and research to practice. So do any of you have thoughts about recent research findings that are right for translation but haven’t been translated yet and that need to be looked at more carefully?

DR. STAHMER: Well this is Aubyn and I think one of the challenges that we have with the implementation and this may go to the infrastructure question – I’m not sure but really the level of support practitioners need from their organization in order to sustain practices for longer periods of time and I’m not sure that these practitioner trainings have really addressed that sort of infrastructure that you can see.

I can’t remember who was talking about their statewide implementation and how that support really is facilitating practitioners and I don’t know that we’ve got that kind of complexity in our implementation studies as well as the complexity of the autism interventions.

((Crosstalk))

DR. DANIELS: Sorry, can you…

MS. CRANE: This is Sam. I would add billing in there in reimbursement rates. I don’t know if that’s been the subject of a lot of research, but a lot of people – especially in context like health home, when people are asking why, and we have research on this why isn’t it actually happening.

Reimbursement rates are often cited and that could be the focus of some of our economic research, like how do we have adequate pay scale to not only incentivize the development of a workforce, but also enable people to build their time for something for practices that are evidence based.

DR. DANIELS: Thank you.

DR. BROOKMAN-FRAZEE: This is Lauren, I want to reiterate and support the comments about at an organization level intervention. If we think of from implementation science the different inter-levels of implementation and outcomes at these levels and interventions at these levels.

I think that we focused a lot on very high level policy and policy influences on implementation as well as on provider training that they’re certainly outside of the area of autism and increased focus on organizational interventions that may include the incentives and funding that other implementations support that leaders in different service systems and within an organization may employ to support the initial implementation sustainment of evidence based practices within their organization.

DR. DANIELS: Great, anyone else want to jump in with comments on this?

(No response.)

DR. DANIELS: So are there any opportunities right now from being on the ground in the field for practice to inform research that you are aware of that you think are ripe opportunities that haven’t been taken yet.

MR. DAVIS: Hi, this is Daniel. I think that right now a lot of the work around person-centered planning is starting to reach, I think, rightness, in terms of being ready to be employed on a larger scale. So I would think that that's an area that is potentially fruitful.

DR. DANIELS: So you're talking about research to practice or practice to research?

MR. DAVIS: Well, it would be essentially research to practice.

MS. CRANE: This is Sam, in terms of practice to research in the communication field, we're seeing this absolute explosion of different kinds of AAC strategies and again, that includes both high tech and low tech AAC strategies and unfortunately there is almost no research still on different strategies. There is research on like a couple – only a couple of tools and so that could also be a good opportunity for practice and for research. So we'll go out there and see what people are doing and see if we can get research validated.

(Long pause.)

DR. DANIELS: Any other comments on that? So I'm kind of moving – we've been discussing both services, research and policy issues all along and so they've – we've been discussing them fluidly, which is just fine. I wanted to give you an opportunity to comment on any innovative programs or recent policy changes which we've talked about some, but have addressed some of the gaps or needs in this questions research area.

So are there any particular programs that you can think of that are modeled that are worth exploring more?

(No response.)

DR. DANIELS: And in addition, the last question that I had in the discussion of services and policy changes was – what are the most significant service needs or gaps that are not being addressed. And we've been discussing some of that all along as well, but is there anything else that people feel like they haven't had a chance to comment on so far that you feel are major gaps that needs to be discussed.

(No response.)

DR. DANIELS: All right I'm not hearing any, I'm going to move on to the next part of the agenda, so we're ahead of schedule which is good. We wanted to talk with you a little bit about the aspirational goals that the committee set when they put together the strategic plan.

So the aspirational goal for this chapter on services was, "Communities will access and implement necessary high quality evidenced-based services and supports that maximize the quality of life and health across the life-span for all people with (AST).

Do you still feel that this is an appropriate long term goal for Question 5 of the strategic plan and I also wanted to ask you what you think, how you think we're doing in terms of moving in that direction?

MR. DAVIS: Could you repeat the way it's worded one more time.

DR. DANIELS: Yes, sure. Sorry I didn't – oh, it's in the agenda too – if you've got the agenda in front of you. We have it typed there for you but it's "Communities will access and implement necessary high-quality evidenced-based services and supports that maximize quality of life and health across the life span for all people with (AST).

So it’s pretty broad but wanted to see if you still feel like that reflects the spirit that the committee should be moving in – in trying to continue to advance this area.

MS. CRANE: So I’m sorry to be – so – sorry this is Sam.

DR. DANIELS: Can’t hear you very well.

MS. CRANE: Okay, I’m not sure why – is this better?

DR. DANIELS: Yes.

MS. CRANE: So when we say again, this is for the purposes of the summary not the portfolio analysis, cause when we talk about life-span that would be under Question 6. I’m sorry to be nick-picky about the…

DR. DANIELS: Yes, this is just the really the chapter, yes – so.

MS. CRANE: Okay.

DR. DANIELS: But this is – because we’re talking about service systems that may, you know, not necessarily be focused on one segment or another, but be for all people on the spectrum. So that was how the committee felt at the time when it put together the strategic plan that they wanted to and I think they also wanted to infuse the lifespan perspective wherever possible throughout this strategic plan, so even though there is a chapter that’s focused on life span issues specifically. But do you still feel comfortable with the aspirational goal?

MS. CRANE: I think so.

MS. HAWORTH: It still feels comfortable to me.

DR. STAHMER: This is Aubyn. I really love this goal. The only thing I might add is at the end for people with (AST) and their families, given the concerns that have come up about family well-being and safety and caregiver support.

DR. DANIELS: I think that would be well in line with wording that the committee has used in many other documents in the past. So that would be a good suggestion. And how do you feel about where we are in terms of getting to this goal, or anything that committee can do to try to move us forward more quickly.

I know you’ve been discussing this kind of all along so maybe it’s something that you’ve already discussed. So if it’s okay I will move to just wrapping us up and talking about what we’re going to be doing next, unless anybody has any more comments on the content. I really appreciate how people have been sharing different ideas and we’re trying to keep some notes here so that – and plus there will be a transcript to help you with your writing task.

DR. PRATT: Susan, this is (Kathy), I think for me, you know, I love the aspirational goal. I think, you know, the challenge for all of us is, you know, there are pockets in our state where people don’t have access to these things. And I think it’s that – these things are available and accessible to folks and I think right now we’re at that stage where these practices are not common practice. And how do we take what we know are good practices and make them more commonly and equally available practices.

DR. DANIELS: Great, thanks.

MS. CRANE: This is Sam, I also wanted to say that, you know, this is going to be a place where the EPST guidance that Melissa discussed is going to be really critical because the previous state – the previous situation was that you had to be on a waiver program in Medicaid in order to get access to a lot of different autism related services.

And waivers were really difficult to get in to and we actually have seen that as a really significant source of disparity because people who are under resourced who don’t really know where to turn to for services.

At first they might take a long time to even get on the waiting list. Many waivers are regional and so they don’t even cover the entire state. So by saying that these services have to be covered for all children on Medicaid, we’re really expanding the number of people who have access and who have the ability to get these services. And I think that's going to reduce a lot of disparity.

DR. DANIELS: Thank you. Others with comments. So the group task going forward is going to be to start working on a draft for this chapter, and so I will be working with my team and the co-chairs to come up with an outline and then the co-chairs will be helping to organize volunteers to help draft or edit different portions of this, and the entire working group will have access to be able to review and offer suggestions for edits.

So we will be working on that over the next couple of weeks to try to get that together and be sending that out by e-mail. On the following call, we’re going to then try to narrow this down to coming up with three objectives that can represent really broad goals that this group feels would be important priorities to move forward in this strategic plan.

And so these would be broad goals related to services and could be related to any of the themes we’ve talked about today. By making them broad, hopefully you can cover more than one little topic in each and be able to capture what you think are the really key ways that the field can be moved forward, both in research and delivery of services.

So be thinking about that over the next couple of weeks before our next call and you'll be hearing from me and/or Shannon and David about this before our next call. So we'll have the task of developing those objectives. If you have suggestions about potential objectives in the meantime and you just want to fire off a few thoughts, we can collect those and compile them and bring them to the next call for discussion.

So feel free if you think of some areas that you think would be good ones to make into some kind of priority for the strategic plan. So feel free to just e-mail those to us and we'll put them together. So any other questions before we adjourn for today.

MS. HAWORTH: Do we have a next call time set?

DR. DANIELS: I don't believe the third call has been set for any of the groups yet, so you'll be hearing from our office about that. We've been doing the doodle polls and trying to see; which were the dates that the most people could attend the call, so we should be in touch hopefully this week with the third call information.

And of course, all will be placed on the web and will be sending it out by e-mail. And anybody who's listening to the call that's not already receiving IACC emails, you can go to our website and request to be added to our mailing list. Well thanks so much for participating in this discussion. We really appreciate everyone's time and willingness to share their expertise. We will be talking to again in the near future, and hope you have a nice rest of your week. Thank you.

GROUP: Thank you.

(Whereupon, the conference call was adjourned.)