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INTERAGENCY AUTISM COORDINATING COMMITTEE

SUBCOMMITTEE FOR SERVICES RESEARCH AND POLICY

STRATEGIC PLAN QUESTION 5 and 6 PLANNING GROUP FOR SUBGROUP COMPARATIVE-EFFECTIVENESS RESEARCH AND PATIENT-CENTERED OUTCOMES RESEARCH (CER-POR)

CONFERENCE CALL

FRIDAY, OCTOBER 12, 2012

The Planning Group convened via teleconference, Denise Dougherty, Ph.D., *Co-Chair*, presiding.

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PROCEEDINGS:

Ms. Gemma Weiblinger: Thank you very much. Hello, everyone. My name is Gemma Weiblinger, and I am temporarily acting as the designated Federal official for Dr. Susan Daniels, who is currently out on maternity leave.

So welcome to the conference call to discuss the update for Question Numbers 5 and 6 of the Interagency Autism Coordinating Committee Strategic Plan of 2011.

I will now turn the call over to Dr. Denise Dougherty, who will lead the discussion about the update of the Strategic Plan with respect to services research and policy. Dr. Dougherty?

Dr. Denise Dougherty: Thank you very much, Gemma. We should probably have a roll call. I can call the names of the people who are supposed to be on the call. Idil?

Ms. Idil Abdull: Yes, I’m here.

Dr. Dougherty: Okay. Lisa Simpson?

Dr. Lisa Simpson: Yes, present.

Dr. Dougherty: Jan Crandy? Okay, I think she wasn’t. David Mandell? No. Tristram Smith?

Dr. Tristram Smith: Yes.

Dr. Dougherty: All right. Zack Warren?

Dr. Zachary Warren: Yes.

Dr. Dougherty: Okay. Gemma and Elizabeth.

Dr. Baden: And Sarah.

Dr. Dougherty: And Sarah. Great. Okay. I’m Denise Dougherty.

So first I want to thank folks for sending in their responses to the two – it’s very hard to distinguish, the two questions for the Strategic Plan, which are on services and lifespan issues, which we have divided into topics – the topic of comparative-effectiveness research and patient-centered outcomes research as a subtopic of our Services Research and Policy Subcommittee. So, we got those.

And I want to make sure that everybody got my attempt to try to synthesize those and put them in some kind of order – not the perfect order of course, and boundaries are never perfect. But did you get the documents that were sent today?

Dr. Smith: Yes.

Dr. Dougherty: Okay, great.

Dr. Baden: Yes; thank you, Denise.

Dr. Dougherty: Okay, thank you. So I thought what our next step – you also got the timeline – so our next step is to submit two to four pages per topic to the Subcommittee Co-Chairs.

Now that would be submitting it to myself and David, but as we agreed, we wanted to give you a chance to think about these topics, identify any recent findings that you thought were important to include in the research Strategic Plan, and then identify research questions that should be identified in the Strategic Plan for research on autism spectrum disorders.

And we talked last time, and Zack you weren’t with us. So I think we agreed that our focus would be not on CER/PCOR in the clinical sense because we felt that the other Subcommittee, which is Biomedical and Translational Research, would be dealing with that question under the Strategic Plan Question 4, which is treatments and interventions – which treatments and interventions will help. So that's to explain the lack of mention in the research questions here of clinical, very clinical research questions.

Of course, it's very hard to often make the cut, have a boundary around what's a clinical question versus what's a service question. So I might not have gotten that perfectly.

So, what I thought we would do here is actually I would go through the questions that we have, and then Idil sent a couple of more topics for review for thinking about, which you all have. I believe you all received those emails from Idil just in the last few hours or so?

Dr. Smith: Yes.

Dr. Dougherty: Okay, great. And so that’s one way to think about what are we missing.

And get your feedback on how these are being articulated. Are they being articulated correctly? Are we hitting all the most important crosscutting issues? And then, what are we missing?

So I’m actually going to ignore the addendum Question 1, which is what have we learned since January 2011, even though some were submitted. But I think at least my real concern is developing a research agenda for the future because we really haven’t. Or we, the IACC, has not really had a services research agenda – a very robust one in the time that it’s been doing these Strategic Plans.

The previous iteration of this Subcommittee was called the “services and something or other Committee,” but it didn’t have research in its title. So I think I’m more concerned about getting the research agenda out, especially getting something ready to circulate to everybody who’s going to come to the workshop on October 29. Excuse me, go ahead?

Ms. Abdull: This is Idil. So I was just trying to think what they had. I think they had “services and safety” maybe? But it wasn’t research; you’re correct.

Dr. Dougherty: Yes, okay.

Dr. Simpson: So, Denise, this is Lisa, and I owe you some more questions. I didn’t get those in.

But I guess one question I had, having reviewed the materials you sent today, was – and forgive me if this was already covered – but just thinking about a more traditional services research framework and categories of questions, and then thinking about those from the CER/PCOR perspective, especially.

To what extent are things within scope that are around coverage and access, benefit design, provider capacity, and then you know, the things that are clearly within scope in terms of care patterns and then ways to improve care for children with ASD and all the various interventional approaches. So I wonder how much of what I just covered very broadly is within scope for us?

Dr. Dougherty: Well, it’s in scope for the Services Research Subcommittee, but we have actually had – we have four other topic-specific groups that are working.

Dr. Simpson: Okay. So we’re very much on the CER stuff.

Dr. Dougherty: We’re on the CER stuff, yes. The other groups are access and coverage, quality of care, education/employment, family support.

Dr. Simpson: I guess maybe I’m pushing this a little too far, but again the CER, again we’re focused especially on the systems-level CER questions as far as clinical interventions. So certainly one could think about an access question in a comparative-effectiveness frame, and are they going to consider those?

Dr. Dougherty: That is a good question, and I think those are the kinds of things that we will work out at the meeting itself, at the workshop.

Dr. Simpson: Okay. All right. There are a host of access questions for these children in terms of access to specialty care, referral services, and different ways to – the role of telemedicine and different workforce deployment models and team-based care and referral strategies, where you could take that from a comparative effectiveness – and particularly for these children in rural settings. You know, what’s the role of telehealth consultation and different ways of doing that in terms of improving access to care.

Dr. Dougherty: Absolutely. And I think it would probably be best, so that those don’t get forgotten, that we include them in our CER/PCOR list of questions. And then if the access and coverage group has additional ones that can be turned into CER/PCOR-type questions, we can always do that.

We’re not going to be submitting to the Committee as a whole or to OARC, the Office on Autism Research Coordination, you know, these things organized necessarily by these five topics.

Dr. Simpson: Got it. Okay. That’s helpful.

Dr. Dougherty: Okay? So, and it’s very clear there are crosscutting ways to group these topics. And you’ll see that when we go through the questions.

Dr. Simpson: And then an overarching format question is that so much of CER/PCOR is about what works best for whom. And so as I read the questions, any one of the questions could have subcategories specifying subgroups within that that you want to make sure that your study is powered to be able to answer the question for. And so I wondered if that could be kind of a framing point rather than having to repeat it under every question.

Dr. Dougherty: Yes. And that’s why in a lot of these questions these rows on Table B – a lot of them but not all of the – and all of them should probably have it – add variation by population.

Dr. Simpson: Okay. Or maybe just do that as a framing thing, framing comparative questions.

Dr. Dougherty: I mean, our concern – and, Idil, jump in here – is when we kind of have it as a framing question when push comes to shove, and the question gets taken by somebody and edited and put into another document – that framing gets lost.

Dr. Simpson: Got it. That’s fine.

Dr. Dougherty: But I’m not sure how to do it without being really, really redundant. And I know that the OARC, the Committee, wants this to be a brief addendum.

Ms. Abdull: Sorry, I was trying to be polite for a change and not cut anyone off. To answer the question of is the – because

I’m also on the access and coverage Planning Group – but I have not seen what the experts sent, and their deadline was yesterday.

So it also, even though we’re all within IACC and the Services Subcommittee, then it depends on the leader of that planning group. Because Denise sends in – we’re all on the same page, but I don’t know what’s happening with the other ones. So I just sort of sent my take on it. But maybe I’ll ask John if we can all also talk about it.

But from what I’ve seen on those emails, it’s only addressing access to services and coverage and who pays for it. So, for example, public insurance from CMS versus private insurance. And the people or those experts are at Autism Speaks and a couple of people from CMS.

And you know, it varies. Even for the private insurance, there’s only 37 or so, but that’s only for state-regulated insurance, so it doesn’t really cover everybody who is self-funded. And then also CMS doesn’t have the EPSDT. There isn’t a way to cover, have access for autism services, which means that states have the option. And there are only 12 states, I think, that chose to do the option. But they don’t do it across the lifespan. They do a very limited amount, usually early children, you know, early intervention.

And so I think that group is only focusing on who has access and who has coverage and what have they got. So clearly, there are more gaps.

And again, I have not seen it, but I don’t think, unless I’m mistaken, it’s covered the questions that we have here for this CER/PCOR of what do we know about the effectiveness of different approaches to providing services.

On waiting lists, waiting lists – I mean, if you’re an autism parent, it’s a mile long. So even if you really learn the signs and you want to get a diagnosis at 18 months and you think something is wrong, sometimes you could wait a year even in Minnesota. And it’s even worse in rural areas.

Then to get the intervention, it’s another 2 years. So that’s not being covered by access and services, so I would hope that we cover here the what do we know about the waiting list, how does that affect the ultimate outcome, and then what do we need to know.

How do we address – I think somebody said “provider capacity.” A lot of providers are just not – they don’t have the know-how. A lot of providers finished school before autism was a hot topic. So even pediatricians don’t really know how to help the children or the parents.

Dr. Dougherty: Yes, and just to remind you – thank you for that – that what we’re currently thinking of is – at this workshop – that we will have a brief time in the morning after some introductory remarks for each of the workgroups – each of the topic-specific groups – to get together and refine what they’ve already done.

And then the idea is to bring all of the topic-specific lists of questions back to the large group, which would be all of the topic-specific groups and all the Subcommittee members – the experts and the Subcommittee members – and then flesh out what we’re missing.

So, I think – because what I’m struggling with is how to turn some of Idil’s questions into CER/PCOR questions.

Dr. Simpson: Yes, because we’re really just putting a framework for answering like “what if?”.

Dr. Dougherty: Right.

Dr. Simpson: Not how to [Inaudible].

Dr. Dougherty: I mean, you can see CER of comparing different approaches to reducing waiting lists. But provider capacity is more of a descriptive question about what’s the provider capacity, as I understand it.

Dr. Simpson: Right. And I think there’s the comparative-effectiveness question again, touching on the systems perspective of whether – and it’s sort of provider ability to deliver care to these children. And so there it could be a comparative question in terms of different approaches. And one could frame it as a quality improvement question in terms of ways to improve the quality of care and do different modalities of provider education or support, you know – all those things that would be getting at how to improve provider capacity, not just documenting what it is.

Ms. Abdull: Right, I agree. I think how to improve – in terms of research, we don’t really even know – there is – even in Minnesota we have the medical home. But I’m not sure how well that’s being replicated across the United States. So knowing what worked and then putting in a question, a policy question so that parents are not just hearing, “Oh, we know there’s a gap.” But at the end of the day, we want to hear, “Here’s how we’re going to address that gap.”

Dr. Simpson: Right.

Ms. Abdull: So I would ask that researchers put not just the problem but also solutions to the problem.

Dr. Dougherty: Right, and that’s what we’re trying to get at here.

So let me go through the questions and then see if some of your issues are included in these questions, or if we can flesh out the questions more to make sure that these critical issues like waiting lists and different provider approaches and provider capacity are included.

Or if they’re not included here – I’ve got my parking lot here, so that David and I – when we’re putting all the topic-specific groups’ lists together, we make sure that these questions are addressed as a services research question.

Ms. Abdull: Okay.

Dr. Dougherty: Okay? Okay. So starting with – this is Table B, and the heading – I’ll just say how I organized this. So service or policy is the first column; that’s kind of, what’s the intervention, what’s the question? Then the age group, because we want to be sure to cover the lifespan. Then, what crosscutting issue has been already addressed in the question that you submitted. And then the question itself – sometimes edited, sometimes not – then who gave us the question. And that’s not that there’s going to be a citation in the report, but that’s kind of just for me and David to know where the question came from so we can track you down if we need to. And then whether there’s a potential issue, and the potential issues vary by our structure versus research questions.

So one is early intervention, which is the starting place, right? So early detection. Tris submitted a broad question – and of course I don’t have all the context here but – “What is the impact of efforts to encourage early detection?”

And then the second question under early detection is the comparative effectiveness of tools for early detection, because there are different tools being used such as screening tools.

Ms. Abdull: Could I add the screening tools to be culturally responsive?

Dr. Dougherty: Okay. Cultural responsiveness, okay.

Dr. Simpson: The question around screening tools – that seemed to be more like a clinical intervention rather than a systems. I think we should keep it, but you guys will figure out where it goes.

Dr. Dougherty: Well, yes; we'll figure out where it goes. And so it could be clinical.

Ms. Abdull: Even if clinical, if the tool is to get early identification, early diagnosis, it still needs to be culturally responsive because –

Dr. Dougherty: Absolutely.

Ms. Abdull: – autism, so much of autism, is about behavior and behaviors in a culture. And so our culture is going to be different than mainstream Caucasian American culture. And if I asked a lot of those questions – “Does your child do imaginary play or social skills?” – I’m going to say no, but it is my culture. We don’t do that, even for neurotypical kids. Whereas for Americans non-minority that’s normal developmental that they expect the kids to do.

Dr. Dougherty: Okay.

Ms. Abdull: Different for Hispanic and other ethnicities.

Dr. Dougherty: Absolutely. So this next is several questions. I kept them together, though tell me if they need to be separated. And “What is the impact of efforts to increase access?” So that’s a systems question.

When implemented on a large scale, what strategies successfully reduce the age of diagnosis, increase participation in early intervention services, and reduce disparities experienced by underserved groups.

Now, is that the same question? Are

there small-scale efforts that should be looked at separately from large-scale implementation of strategies? Are those two separate questions or one question?

Dr. Smith: I guess I thought of it as one question although in terms of the early detection issue.

Dr. Dougherty: Okay.

Dr. Smith: So yes, sorry. I unfortunately have just a whole string of questions, because I couldn’t separate them.

Dr. Dougherty: I feel your pain. That’s a really good loaded question though.

Okay. And then, “Do these strategies lead to improved outcomes, and what are the costs?” Now, that’s a services question.

Dr. Simpson: And this [Inaudible comment] another question, issues that throughout, when we talk about outcomes, I want to make sure that we talk about outcomes that are both clinically measured outcomes as well as patient-reported outcomes and experience of care and that they’re all important outcomes.

Dr. Dougherty: Yes, okay. So that’s important, because I grouped that on the last page of this table, under methodologic research – which is the need to measure and index improvements in core symptoms of psychiatric comorbidities and then develop quality-of-life measures. I think you’re adding something else, Lisa.

I don’t know the extent to which those kinds of measures are already available.

Dr. Simpson: I don’t know either. But again – particularly on cultural diversity those experiences of appropriateness of care and quality of care and patient-reported experiences are going to be essential to understand how to match effective treatments and deliver them appropriately for diverse populations.

Dr. Dougherty: Okay.

Ms. Abdull: And, Denise, this is Idil. That – I love that question. And I think we have a quality of care planning group. So I hope they are addressing it, too. But I think the idea of separating clinical and patient-reported is really important. Because, while clinical is very, very important for those of you that do clinical research, but from patient point of view, I think it’s an important tool based on what the clinicians are doing what are the patients reporting. Are they satisfied? Not satisfied? Should there be changes? Because in the end of the day, it should all be about a patient.

Dr. Dougherty: Right. Right. And I haven’t come across a patient experience of care for families with a person with autism.

So, but what about the – so we have that added to the outcomes question, the measure development questions. What about this issue about what are the costs? Should we have that as a separate item – comparative research on costs?

Dr. Simpson: Absolutely. I mean, the cost for families is tremendous –

Dr. Dougherty: Okay.

Dr. Simpson: – and then contributes to huge barriers.

But before we leave the outcomes question, I’m just a little nervous again not knowing how you are going to put this all together, that if the question of types of outcome only comes in under the methodologic section – that then a question around any kind of intervention impact on outcomes, people might think only clinical outcomes.

And so maybe if we could just, I don’t know, everywhere say a broad range of outcomes. Because there’s clinical, patient, and – what you just raised – is cost outcomes as well. So I don’t know how to handle that, but I wouldn’t want folks to think that we’re only interested in the clinical outcomes when they look at the intervention question.

Dr. Dougherty: Yes. And I think that’s really important. And the NHLBI did something a couple of years ago, which they – were kind of – they had all this research on asthma, but all the grants were studying different outcomes, and all of the surveys were collecting different data. So they had a meeting to actually come up with what the outcomes should be that should be studied and how they should be defined. So that might be a research infrastructure question for this group. Because there are a variety of outcomes, and not all are addressed in every study or question.

Ms. Abdull: I think that the cost should be all – in addition to this – but it should really be emphasized strongly because the cost to families is high. There also is the reason why intervention and diagnosis and all of it is so late or nonexistent because the cost of autism is viewed as very, very expensive.

So, even the public and the private insurances don’t want to pay. Because it varies from state to state. It varies from county to county, which is why you have some states pay for it, some don’t. So if we think about the cost and how much should it cost and who should decide that? What should ABA cost versus Floortime versus speech versus OT? In addition to the cost to the family, but even the cost of services varies literally by state and even by within that state that often people – public and private – just often shy away from paying for any autism services because they think it’s so expensive.

But they’ve never really done the consequences of not paying for these services or providing these services to these families. What happens if we don’t? Are group homes more expensive? Are institutions more expensive? I don’t know if there’s ever been a study done of not doing the intervention, especially early and throughout life across the spectrum and across the lifespan. If it doesn’t happen, what are the consequences or that cost?

Dr. Dougherty: Cost-benefit.

Dr. Simpson: And to add to that – again maybe in the message section or infrastructure – better defining and understanding not just the direct but also the indirect costs, you know, in terms of time lost from work, having to stay home, or forego a job – all those additional costs that families bear or sometimes bear when they have a child – so a broad definition of both direct and indirect costs.

Dr. Dougherty: Good idea.

Ms. Abdull: Yes, indirect might even be more than direct. I mean yes. Indirect is more. I don’t know of any autism family who has a regular job, can succeed in their career, and steal deal with just one, let alone when you have multiple kids with autism. It’s even worse.

Dr. Dougherty: Okay. So now onto the next one. So we’ll make cost a separate question and do some developmental work on methods.

So, the next question is early intervention focused on diagnosis and treatment to address the increased amount of screening and identification of children with ASD and the increased number in the population.

So, Zack, this is yours. And “development and rigorous study of large-scale programmatic initiatives that result in practice change and are capable of dissemination to traditionally underserved populations.”

Now this one, David may take and put under quality of care, which I actually thought was quality improvement. But –

Dr. Warren: This speaks to that idea of are we able to sort of compare models for –

Dr. Dougherty: Right.

Dr. Warren: – implement, you know, for actually moving from practice parameter to actual practice and what are the factors in the system level whether they be economic incentives, extra training do-the-right-thing sort of approaches. What are the actual sort of mechanisms pushing this? And I’m not actually saying that there’s enough work out there, saying that we can, but there’s no sort of comparison data or comparison efforts to say, “Well, what are the methods for moving this?” – not just from those isolated efforts toward the populations that we work with.

It overlaps somewhat with Tris’s earlier question, too. But this adds in that idea of workforce that we’re talking about as well.

Dr. Dougherty: Okay.

Ms. Abdull: Would provider capacity or even knowledge be part of that? Because that’s where –

Dr. Warren: Yes. That’s exactly what it’s getting at, is saying how we’re actually translating from simple screening toward [Inaudible] medical home [Inaudible comment] encapsulating all of that as part of this.

Dr. Simpson: And this is Lisa, just jumping on this. So piggy-backing on what you’ve been saying – and it’ll probably go in part of it on the quality of care one, but I’d be interested in the extent to which patient-mediated providers’ behavior change has been studied and how effective it is. Because it’s certainly been studied for other activities, whether it’s antibiotic use for otitis media or immunizations. But the patients can be very effective in influencing provider behavior.

Dr. Dougherty: Okay, that’s –

Dr. Simpson: Again, I don’t know where it goes in your structure.

Dr. Dougherty: Yes. I’m putting it in the parking lot under quality.

Ms. Abdull: That is an awesome observation. Thank you very much.

Dr. Dougherty: Yes. And if you have any – if any references come to mind, Lisa?

Dr. Simpson: Yes. There’s a good one from North Carolina. And then Howie Bauchner did the antibiotics one. And I think it was Steve Downs when he was at North Carolina did the immunization one.

Dr. Dougherty: Great. Thank you. I know how to find those people.

Dr. Simpson: Yes, okay.

Dr. Dougherty: The next one is separate but – this may be my naiveté working on this particular issue – high-intensity early intervention.

So the questions were, and these are probably from Tris and – I don’t know who they were from – sorry. “How do such high-intensity programs work in real-world settings? What factors moderate treatment response and how treatments might change the response to early treatment?” And I think that’s a separate question. And “what measured effects of early intervention programs are seen in terms of later child, family, and system outcomes across diverse patient populations?”

So is this a separate question from the question about early intervention programs in general?

Ms. Abdull: Well, it’s the same, but I think the word “intensity” has different meanings. Because intensity sometimes can be viewed as 40 hours versus 10 hours. Whereas with some methods, their intensity is 10 to 20 hours. With others, they will say in order for this type of intervention to work the child has to do 40 hours.

And so the last email that I sent, I think there was a study last year where they said they really don’t know whether it’s Floortime, ABA. I think they gave the medications high marks, but everybody else, all the other methods, got really low marks because it hasn’t been repeated enough to know does 40 hours always works better than 10 hours.

Dr. Dougherty: So what you might do is be sure to include in this question about the impact of early intervention is be sure to analyze it, compare it by levels of intensity.

Dr. Warren: Well, I think I wrote this one, actually, and Tris actually put something very similar in, but [Inaudible comment] wasn’t necessarily looking at a comparison of intensity per se in that way. But I think this matches on with Tris’s earlier question as well. Saying okay, so we have these controlled trials for this, but we don’t have the extension data toward actually making this work in real-world settings and understanding particularly the underserved in particular sort of broadening our outcome questions, right.

We’re making sure that we’re not – this came up earlier – that we’re not just focused on one specific outcome, whether that be cognitive or language or adaptive, but making sure to take into account impact on families, impact on systems. And sort of, it frames that idea of cost being not only direct and indirect but human as well, you know. And sort of how do these type of modalities – and this is essentially from the previous comparative-effectiveness research that the only intervention type with the strength of evidence but we just don’t understand the real world or moderating some characteristics of that beyond it. But that was my intent in drafting it.

Tris, I don’t know if you agree with that question or those thoughts?

Dr. Smith: Yes, no; I think that’s exactly right. So it’s really we have pretty good evidence from university-based trials for these interventions, but how do you implement them in the real world and how do you evaluate outcomes and how well does it work in that context, or those contexts, I should say? Moderator variables – I think those are critical issues.

Ms. Abdull: Can I also add, because you also said the underserved community – o underserved populations I think – it’s too bad that David’s not here – but the early intervention time for them is age 6 to 7. It’s not your typical 2- to 3-year-olds. So it’s different; it’s a totally different kind of outcome for when the child gets the intervention years later and maybe not as intense as they would have.

Dr. Dougherty: That’s a good point.

Dr. Warren: – geared more towards what we know in that evidence base of sort of preschool age, 3 to 6, high-intensity works. You know, we have some of the novel stuff stretching beyond that, but there’s certainly appreciation of that.

Dr. Simpson: One of the questions [Inaudible comment] for me is the issue of, and I don’t know where this goes or if it’s even in our section, but the question of fidelity and adaptation. And it comes up from sort of this also dissemination and implementation research frame, particularly that the NIH uses, that for these interventions that have been proven effective in the trials – how much adaptation can you do for local populations and local community contexts without losing the effect size?

Dr. Smith: Great. And that was really my point, was about the comparative effectiveness of [Inaudible]. Actually, I was really more trying to get at that point because it looked as though there needed to be an enormous amount of training to get an effect, you know, to have the community providers do these things and get an effect. And, you know, what would be some models for collaborating to adapt models or more efficiently transferring knowledge on implementation?

Dr. Dougherty: Okay. Well, we’re – this is terrific. We should have scheduled a 2-hour call.

The next item probably, I’m not sure – it’s not in the right order here – but models of ASD workforce development for early and accurate identification of – that’s why it’s here – for early identification of children and adults. So this is a workforce question. So are we okay with this one? Okay.

Then methods and measures. So this is a specific comparative-effectiveness question rather than development of a measure or research infrastructure. Is the skill system a useful platform compared to other approaches to measure results of interventions.

So, Jan submitted this one. So, I don’t know. Maybe this goes with the methodological issues. How do you measure the outcomes? Is this one of the systems? Are we okay with putting it with methodological?

Ms. Abdull: I would say, Denise, and this might not even be so much related to, but in terms of workforce of people with ASD. Knowing what little we know I think we need more research in where should they be working, what kind of training should they get, when should they get it. Is it high school, is it vocational, is it early on at 10 or 12?

All these things that I – we have five planning groups, so I’m not sure where they would go. If it’s just the one that – because there’s a workforce and education planning group.

Dr. Dougherty: Right.

Ms. Abdull: I think there’s a lot more

that we need to do for making sure that they’re ready for some kind of workforce. And across age, across, not just across the age, but across the spectrum. So someone who’s highly functioning or Asperger’s might be okay and might be able to do a job, but then what does that mean for the nonverbal person? Shouldn’t they also have their quality of care improved if they had a position or a job or they need training to do something?

Dr. Dougherty: Okay. So we’ll flesh out this workforce –

Ms. Abdull: I think that might –

Dr. Dougherty: – to be more about training and deployment. Okay.

So then we’re moving onto page 3, health care delivery system interventions. So first is, Tris suggested this, the impact – I may have changed it a little bit – the impact of variations in insurance legislation on access and outcomes. His wording was how does insurance legislation influence systems for delivering services?

Dr. Smith: I think the – rewording works.

Dr. Dougherty: Excuse me?

Dr. Smith: I think that works, the rewording.

Dr. Dougherty: Okay.

Dr. Warren: Great question. Important question.

Dr. Dougherty: Yes. Important question. And then –

Dr. Simpson: On that question, adding to the insurance dimension. I mean, to what extent do you want anything specific to implementation of the health insurance exchanges and the essential health benefits and how that whole brave new world that’s going to be starting in 2014? I don’t have a specific question, but –

Dr. Dougherty: I think that’s right because states will be doing these differently, and different essential health benefits packages will likely have some kind of impact.

Ms. Abdull: The overall – sorry, this is Idil – the overall thing to remember when we ask [Inaudible comment] is the affordable health care, whenever we have any autism services or coverage other than preexisting condition. So the states will decide. But if I know states as much as I know Minnesota, they’ll decide what’s – they’re very limited – whatever will cost them the very least. And then also, what does that mean if we want to talk about the underserved communities, which mostly have public insurance? Just because a state has private insurance coverage, does that even mean they follow suit and get their public – and submit 1915(c) or any kind of autism-specific waivers to CMS? It doesn’t really mean we need that. So you leave room for even more disparity.

I think – in my opinion – that should be more of a policy that has to change from Congress. They have to change the EPSDT laws to include autism services. And I don’t know how, but they have to somehow make it so that the state insurance exchanges have some language for autism services and coverage across the spectrum and across the lifespan. And they just don’t right now. It’s all up to the – left to the imagination of the states.

Dr. Dougherty: It’s not just legislation. It’s regulations by the states as well. Okay.

So the next grouping was “medical home,” which was mentioned a lot. The first one is on the comparative effectiveness of training of primary care providers to improve care in the medical home. And I’m assuming this one assumes that all primary care practices are medical homes. Or is this specific to designated medical homes?

Dr. Simpson: And I would also broaden it. Because the question is some specialty practices are trying to become medical homes for severely chronically ill kids. So I wouldn’t assume that for ASD, one, that we know what the right model is. I have my belief system, but I don’t think that’s been well looked at.

The other thing is that I also – the question I have is do sort of generic, you know, does medical home certification by NCQA or anybody else or other ways to get to become a medical home, to what extent does broad improvement in the care and the practice ultimately translate into quality improvement for ASD kids? Because there’s an assumption there that the impact is across all locations that providers see, but it may not be.

Dr. Dougherty: That’s a good question.

Ms. Abdull: We have that in Minnesota but it didn’t trickled down to people in the community.

Dr. Dougherty: Okay. So the next one is focused on children and adolescents, and it’s about family support within the medical home again. So, and it would be comparative effectiveness of different decision aids, toolkits, and other family support strategies in the medical home. Any thoughts on this?

Dr. Simpson: No, I think that would be very good in terms of – particularly with the PCOR focus is making sure that it’s trying to include patient empowerment and patient-provider partnership. So I don’t know to what extent those words fit, but I think that’s an important part of it.

The other thing is, and it hasn’t come up yet. I don’t have the document right in front of me, so I can’t remember if it was on the list, is the whole set of questions around the extent to which deployment of electronic health records and health information exchange may or may not help improve the care and the outcomes for children with ASD or adults. That’s such a huge policy question, is the transformation of the practice environment.

Dr. Dougherty: That’s good. May come under quality improvement, but we can make sure it gets in here somewhere.

And then the next one I think is the question you were asking, Lisa, comparative effectiveness of models for large-scale implementation of the – no, it’s different. Large-scale implementation of the medical home. But that, medical home certification, is sort of the large-scale implementation.

Dr. Simpson: [Inaudible comment].

Dr. Dougherty: Well, we can just add your specific question to that.

Okay, then we have – moving on.

Dr. Simpson: But we also haven’t talked about – and I think this is maybe under methods or development and it’s way down the line – is the issue of reporting – I mean the development of quality measures; I assume that’s in quality improvement.

And then a system strategy is to do public reporting on quality measures, you know, in terms of one of the applications that the measures once they’re developed. So, you know, there are sample size issues, et cetera, et cetera.

And then also with Section 1311 and 2717 of the Affordable Care Act, you know, the health insurance exchanges and the health plans have to report to exchanges and the Secretary on their provider reimbursement models and what the plan is doing to try to improve quality of care. I wonder to what extent any of that will include information on autism services?

Dr. Dougherty: That’s a good question.

Ms. Abdull: Where do you come up with these good questions, I have to say? I want to be inside your brain.

[Laughter]

Dr. Dougherty: You know, these are questions that are relevant to lots of kids with special health care needs and lots of adults also.

Ms. Abdull: They are. They just hit – yes, they’re right to the point. I love them.

Dr. Dougherty: Okay. So preschool environment interventions, comparative effectiveness. And this is your – Tris, I think this is you. Maybe you can wordsmith this –

Dr. Smith: Yes, and I was really less interested in that question than – you know, I think the issue that came up for me in those studies was that it was very hard to get the models implemented effectively and accurately in community settings.

Dr. Dougherty: Okay.

Ms. Abdull: I think not all of them are university based, but we don’t know how effective they were on the ground in community settings for real families and real children.

Dr. Dougherty: But I still think – I’m trying to get CER and PCOR away from strictly medical stuff. So preschool environment interventions, comparative effectiveness of those, might be a good question.

Dr. Simpson: Absolutely. When we did the IOM list of 100, and there’s just that one autism question on it in the top quartile, but there were other questions that definitely went outside of the medical setting. There were some on oral health, talked about school. So I think it’s important to include diverse settings of potential intervention. So that we reach children where they live, learn, and play.

Dr. Dougherty: Yes. Okay. Now –

Ms. Abdull: Now, sorry Denise, for the preschool, is collaboration with various methods of treatment and services because they seem to all cancel each other now for the parent. And what I said in my email, that it’s just so stressful. As a parent, you don’t know what expert to believe and where to take your child. So, and I believe, hopefully, the other group is doing which therapy works best. But I think it matters now on our side because parents – that adds more stress when you don’t know where to take your kid, which therapy is going to work. And why don’t they collaborate? Are there any studies done on if collaboration and doing multiple therapies for a child, hitting the sensory point of view, hitting the behavioral point of view, what’s the outcome of that?

Dr. Dougherty: Right. Maybe the next question gets to that.

Ms. Abdull: Okay.

Dr. Dougherty: The family support across – for “intervention choices and expected outcomes, comparative effectiveness of approaches to helping families and systems negotiate intervention choice and expected outcomes across resource-strained and available environments.” This is Zack’s question. I think it also gets to Lisa’s point about public reporting and quality measurement. But sometimes those – you need more than the quality measure and a Website showing what the results are.

Dr. Warren: This is that idea of – and I think it latched onto some of the critique and questions regarding medical home, established mechanism, what type – this is what are the programs, what is the effectiveness for the process of having to negotiate these questions? Right on that meta-level, is there anything that we know about within sort of the limited resources, the limited [Inaudible comment] – is there a model for thinking about improving outcomes across all of those different modalities? Not just child specific but family resources, et cetera.

Dr. Dougherty: Right. Okay. The next question is vocational education. That's for adolescents and young adults. That's in the transition period – comparative effectiveness for specific vocational treatment approaches. So that was – Jan and Zack submitted this one.

Dr. Simpson: I have a question for – about a question I'm not sure when it would come up – if I could just throw it out.

Dr. Dougherty: Sure.

Dr. Simpson: And a lot of work is being done on other conditions – but the role of patient navigators in helping families navigate this complex system.

Dr. Dougherty: Okay.

Dr. Warren: That's the framework of the

question that we just read.

Dr. Simpson: Right.

Dr. Dougherty: Okay.

Ms. Abdull: I have to say there isn’t really any good family support. I don’t know if –

Dr. Warren: – a lot of work there.

Ms. Abdull: Yes. And I don’t know if it’s just – not just for this Committee or even the IACC, in terms of just how overall Federal health agencies cooperate with each other to make sure there’s support for the family. Because HRSA is responsible for something in their silo, and CDC is responsible for something in [Inaudible comment] their silo. There isn’t just a connection. Even though autism affects across somebody’s lifespan and across every organ in their body, you don’t have the support of what am I supposed to do, where am I supposed to go, who is supposed to pay, how can I help my kid. You don’t have that support.

Dr. Simpson: So that raises the

question, which is this comparative effectiveness or outcomes of different ways that people trying to integrate services across silos. Because you’re right, it doesn’t happen at the Federal or state level very well, and often it’s left to the community to do this. And so I don’t – different government structures – and that raises questions – you know, how do you more effectively engage parents and family members of ASD individuals in a whole set of stages?

And I can send you, Denise – we just released our brief summarizing the various stages of the research process, trying to think of adapting that services process, and ways to engage the patient/consumer stakeholder in each of those steps.

Dr. Dougherty: Okay.

Dr. Simpson: [Inaudible comment] yes. Because I think that’s a question of what’s the most effective way to engage parents at the individual level but then as an organized group and the advocacy process and the engagement process for driving policy changes at those levels.

Dr. Dougherty: That would be wonderful. Thank you. Okay. So I think we’re out of time just about. We have 2 minutes. No, we’re not out of time.

Dr. Simpson: Well, there are a couple more points that I wanted to just throw out, again building on the HIT – I don’t know what is going on in the autism community but what about the role of registries, with the types of registries for improving – you know, all kinds of purposes. We just had a meeting on registries yesterday.

And then, I didn’t know if there were any role – and this is coming again not knowing anything about this sector – but on m-health applications – mobile health applications – and their potential role in helping families and [Inaudible comment] physicians.

Dr. Warren: Registries are certainly going to come up from the Autism Treatment

Network and the Interactive Autism Network. I’m sure that’s going to be covered in many different spots.

Dr. Simpson: Great.

Dr. Warren: That will not be a problem.

Dr. Simpson: Yes.

Dr. Dougherty: But the role of registries in quality improvement is kind of a separate question. Okay.

Dr. Simpson: Also, the infrastructure for research on –services research – son autism as well. In terms of the various databases that are out there that support autism-specific research.

Dr. Dougherty: Right. So the next ones are kind of general – strategies to promote outcomes for adolescents and adults. It’s more of a – these may be Question 4, you know, biomedical and translational – but I’m not sure they would be covered.

Dr. Smith: Yes, I struggled with that because, and I think Zack noted this as well, we know very little about interventions in this age group, but there are obviously all sorts of important issues. So my mind kind of went to [Inaudible].

Ms. Abdull: So that would be maybe what do we need to know.

Dr. Dougherty: Right.

Dr. Warren: And I think that also the idea of [Inaudible comment] particularly neglected area, but also I think again and again, you know, what is the impact of what we’re doing early and later, et cetera? People are very interested in that [Inaudible comment].

Dr. Dougherty: Okay, that’s a good point, that everything should be –

Dr. Simpson: Another question, and I assume this will come up in the clinical – but it’s certainly being looked at with the seriously mentally ill – is the impact of the, how to say this – and I just had a conference with NIMH about this – about the fact that for seriously mentally ill individuals, their mortality rates as adults from physical health conditions are much, much higher than for individuals with those same cardiovascular and, you know, other conditions without serious mental illness. So again, I don’t know the autism area and I don’t know how big the adult cohorts are that we could study, but is there a disparity in outcomes for other conditions because of the presence of autism?

Dr. Dougherty: Right. There is some GI and epilepsy at least.

Dr. Simpson: Not biologically driven but driven by the fact that it’s so hard to care for these kids that other things get neglected or these kids can’t care for themselves. It’s more a patient and family.

Ms. Abdull: More quality of care. I hope we’re addressing that because that is true, and that’s definitely affecting the quality of the care and the outcomes of the quality of care.

Dr. Dougherty: Okay. And then the last was the methodological issues, which I think we have talked about.

So, we’re past time, but the next step is for me to take your great input today, try to mark this up, and I’ll send it out to all of you and share it with David as well. And next week, David and I get to put all of this stuff together and send it off to OARC and then use the workshop to build on all this wonderful work that you’ve done.

So I just want to say how much I appreciate it. And if you have additional thoughts or questions that should be in here or language that you want, you know, changed here, please feel free to mark this up, or send an email, or whatever. Call me. Okay?

Ms. Abdull: I just want to say as a mom to all of the experts here, thank you very, very much. You are by far my favorite experts. Thank you very much. Don’t let the other side know that I said that.

[Laughter]

Ms. Abdull: I really appreciate the holistic approach that you’ve taken to cover from every quarter, look at it from every lens. That’s very nice.

Ms. Jan Crandy: This is Jan Crandy, and I apologize. I ended up getting called into a legislative meeting. I do have a couple of more studies to send regarding adult care, so I’ll email those out. I wanted to discuss them, and I apologize. And I think that our experts have done an excellent job on what has been put together. Appreciate you.

Dr. Dougherty: Thanks so much, Jan. And thanks to our experts. Okay, so you’ll see something from me soon.

Ms. Crandy: Bye. Thanks, Denise.

Dr. Dougherty: Okay, thank you. Bye.

(Whereupon, at 2:00 p.m., the Planning Group for Question 5 and Question 6 on subgroup CER-POR adjourned.)