

## **MCHB/DRTE Webcast**

### **Autism Intervention Research at MCHB**

April 8, 2010

STELLA YU: Good afternoon. As part of observance of National Autism Awareness Month we're delighted to bring you today's webinar on "Autism Intervention Research at the MCH Bureau". My name is Stella Yu, I serve as the Chief of the Research and Demonstration branch in the Division of Training and Education and I'll be the moderator for this webinar. I want to first thank Hye Young Park and Robyn Schulhof of MCHB for planning today's program. We'll be highlighting some of the work that's been supported under the Combating Autism Act Initiative, including a sample of our 40 research grants, a secondary data analysis grant, and then followed by the two large research networks. We have a panel of distinguished researchers, Drs. Hepburn, Hagner, Butterworth, Kasari, and Perrin. Because of the size of the panel, I will introduce them one at a time before each presentation. In the essence of time I will also keep the introductions fairly short. After the last presentation by Dr. Perrin, we'll have time for a 15-minute Q and A session provided that every speaker is able to stay on schedule.

We encourage you to submit questions any time during the broadcast and we'll address them during the Q and A period. Please type your question in the white message window on the right of the interface, select question for speaker from the

dropdown menu and hit send. Please include your state or organization in your message.

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Finally, at the end of the broadcast, the interface will close automatically and you'll have the opportunity to fill out an online evaluation. Please take a couple minutes to do so. Your response will help us to plan future broadcasts in the series and improve our technical support.

Now I am -- I would like to introduce our first panelist, Dr. Susan Hepburn. She's an associate professor at the University of Colorado in Denver. She's a licensed clinical psychologist and has extensive experience working with families of children of ASD and other developmental disabilities. She's the director of research for JFK partners, the university Center for excellence in developmental disabilities in Colorado as well as the autism courses director for a LEND program. I'll now turn the program over to you, Dr. Hepburn.

SUSAN HEPBURN: Thank you, Dr. YU. I'm pleased to be talking with you all today about our newly funded R40 project concerning the telehealth delivery of a family-focused intervention to promote coping in children with autism spectrum disorders.

We can go to the next slide, please. We're calling this program the TeleCopes project. We're trying to build adaptive coping skills for youth the autism disorders and do it through telehealth delivery. For the past several years my colleagues and I have been working on a live psychosocial intervention for helping families of kids with autism to cope better when they're feeling excessively anxious, really fearful or very worried and can't seem to stop those worries. The lead developer of that intervention is Dr. Judy Reaven and also my colleague Dr. Audrey Blakely-Smith and have had a huge role in developing this treatment package. What I would like to do for a few minutes is describe what that program looks like in the live version and then talk about how we are in this project trying to modify it for delivery across the Internet. So our goals are to translate the intervention package we've been working on for years that has some promising data and provide it to families that live too far away to get here for treatment and then to try to evaluate the impact. Something that might be helpful to know, I'm in Colorado and about a little more than 10,000 individuals in our state are still on wait lists within our developmental disabilities system. So we have a lot of access to care issues in this state. And approximately 15% of our population live in rural areas, 43%

live more than 50 miles from a Medical Center. So there is a large portion of families that are not able to receive services from specialty care.

The next slide, please. So our intervention package is called face your fears and it has been under development for about eight years now. The idea briefly is to bring in a parent and a child with an autism spectrum disorder and interfering anxiety symptoms usually in the areas of separation anxiety, generalized anxiety, phobia or social anxiety and the kids participate in a child group while the parents in a parent group.

Sometimes everybody is together in a large group. The idea is to go through this protocol so the parents are better prepared to support their kids to cope better and the kids are learning better skills and hopefully making connections with other kids. The primary philosophy is to use a modified cognitive behavioral approach to the treatment program and for those of you familiar with that kind of therapy, it is an approach that's thought to be efficacious in typically developing children and we've been working on ways to make these treatments more accessible to persons with autism.

Next slide, please. Very briefly we have two studies that we've -- one that we've published and one that we're still writing up that comment on the hopeful impact of the intervention. The first study was pretty small and about 33 kids using a wait list control strategy and we found that people who participated in the project were reporting some clinically significant decreases in the severity of their anxiety symptoms or more rigorous trial is still being analyzed. We were finally able to use a randomized control strategy with funding from autism speaks and the organization for autism research and

we look forward to seeing how those data pan out as we finish up. The kids we've served are very complex and the completion rate for the intervention is 84.7%. Overall most of our participants are satisfied. 96% of parents said that they were satisfied or highly satisfied. 82% of the youth reported being satisfied.

So when you turn to the next slide, please, you'll see a graph from our data that are being analyzed from the randomized control trial. Kids were either put into the active treatment condition which is listed as face your fears, or they were experiencing treatment as usual in the community and later on offered the chance to come back to face your fears. So here our independent clinician severity ratings of the child anxiety symptom severity, all thoughts owe statistically significant we have concerns when you look at the scale is it going to be clinically significant? We're really looking at losing a half point or so, on a severity scale that ranges from one to eight. We want to take what seems to be working and try to apply it to telehealth delivery in this project.

Next slide, please. Taking a big picture approach, the findings that we think are most optimistic is when we do a semi structured interview called the anxiety disorders interview schedule with our participants, almost 80% of the kids who do the active treatment condition no longer meet criteria for one or more anxiety disorders. So while we don't anticipate that we are curing people of anxiety, what we're hoping is that we might be impacting how much those symptoms are interfering with the child's lives and with their family's lives and so far data on maintenance are encouraging.

Next slide, please. So when we consider the current step in this program of research which we're calling the TeleCopes project we're trying to think about ways to use technology to reach underserved people in our state. So we to plan do three things. We're going to be doing some webinars to try to get information out there to families as well as to professionals across the state. We also are doing our group modalities through some videoconferencing software which I'll tell you a little more about in a moment. And we're developing a website which eventually will have some self-instructional modules that kids and parents can do together as they figure out ways to adjust the way they cope to stressors in their environment.

Next slide, please. So this is a two-phase project within the R40. We just started in September. We're in our development phase and our primary tasks right now are to figure out how to translate this live intervention for Internet delivery. We're getting some wonderful consultation from Dr. Edelman who has done a lot of work in translating technology dissemination and his term retrofitting applies very nicely trying to look at each session that we deliver live and figuring out how we need to change it up so we can deliver it either through group videoconferencing, with parents and kids from their own homes in front of their own computers with their own webcam ras basically chatting in a room or individual sessions where there is one therapist, maybe myself here at JFK having a video phone call with a parent or a parent and a child. In order to develop these programs in a way that's accessible and feasible if our first months we're conducting focus groups and outreach workshops, talking to folks in our community, parents, people with autism of different ages and working hard to make

sure we have technical support documents that people can access the services without being frustrated by the technology. And in a way, our team is kind of perfect for this because as clinicians, we're not technologically savvy so we sort of laugh to ourselves that if we can learn how to do it; it is going to be accessible to the families we work with. Fortunately we have strong support from members of our team who are more technologically savvy and I've been pleased to see how easy it is to actually use these programs and the software that we've chosen to use is inexpensive and readily available. So it could have the potential to be a sustainable kind of intervention delivery method. As we work on these technical guidance documents, we also have some challenges around data security and confidentiality. We've been collaborating quite a bit with our IRB that we're protecting the confidentiality of this interactions and we're trying to pilot our materials through some very directive testing. So, for example, we're currently engaged in delivering some individual therapy sessions through this video phone call modality and today our parent liaison Kristin Kaiser has arranged for four families total to join us in our first group videoconferencing intervention. So there will be four moms with their four kids with high functioning autism joining us on this group video call where we will begin to experiment with how we can deliver our live curriculum through that modality. So it's going to be an interesting experience and we have much to learn as we try this out.

Next slide, please. So as we are developing and refining our protocols the second phase then will be the evaluation phase and here our task is to examine the acceptability, the feasibility, are there technical problems, is this something families

find family friendly? And we're very concerned that we find ways to maintain a good quality therapeutic alliance so we are very interested in are they satisfied with the interaction? What we're hearing so far from families in rural areas who are joining us in this effort is that they are really excited that they have a way to access a professional without having to travel and many of them say even if it isn't, you know, as satisfying as sitting in a room with a clinician, I appreciate that I'll have the chance to interact in a way that is a bit more personal than just on the phone. Then our outcome measures in addition to understanding that process we want to see if this intervention has any impact on the child anxiety symptoms. On their coping skills, on the interference on the family and I think one of our most important outcomes in our live research is the parents' sense that they can coach their kids effectively. That they can come up with strategies to help their kids participate in the world.

So in my last minute or two here I would like to go to the next slide. This is an example of what the computer interface looks like when you are doing an individual interaction. So this is how an individual therapy session might look. These are two boys that were helping us in the pilot effort and both have really reported enjoying interacting through the computer. And anecdotally, although we've had limited experience so far, I'm finding that eye contact is pretty direct. I'm getting more gesture use because they're trying to share an experience and for one boy in particular he seems more enthused. His affect is brighter than when I saw him in person. That could be related to other things but the technology itself seems to create something for us to interact through.

Next slide, please. So then to pull it all together I thought I would show you what a videoconferencing or group session might look like and these are the key members of our team and this has been such a team effort. Everybody putting in a very, very important contribution. So it's Larry Edelman who has helped us consulting on technology. Kristen Kaiser, parent liaison. Audrey Blakely-Smith a clinician, Julie Reaven, and myself. If you can look at that slide and imagine families from around the state, maybe just parents for a parent group or maybe parents with their kids working on goals and objectives where in common they're trying to learn ways to cope better I think it has a lot of potential as a way to deliver interventions. Thank you very much for your time.

Go to the next slide if you'd like and I will turn it over to Dr. YU.

STELLA YU: Thank you, Dr. Hepburn. We'll now transition to our next speaker, Dr. David Hagner from the University of New Hampshire, he has a research grant on family center transition family with student with ASD. He's a research professor and rehabilitation projects director for the University of New Hampshire institute on disability. A certified rehab counselor with over 25 years experience in teaching research evaluation and direct service. He currently directs research and demonstration projects in the areas of transition employment and community living for individuals with disabilities. Dr. Hagner.

DAVID HAGNER: Good afternoon. Thanks and hi, everybody. As you can see, our project is family transition planning for students with autism spectrum disorders, a collaboration between our institute and the University of Maine. We're the university centers of excellence in our respective states. And we recruited students through about eight special education departments of eight schools in each of our states.

Let's go to the next slide. We have a four component intervention package that we have developed through previous projects that we are demonstrating in this project. The first one is we are having parent training sessions for groups of families of the students in our project. And that consists of structured sessions where we teach the adult service system, how it's different from the educational system. Adult service funding and eligibility issues and planning issues. People have the option of going through six evening sessions or three full day Saturday double session series.

Next slide will give us the next intervention. Person-centered planning. An evidence-based planning sessions. Usually in an individual's home with a person, their family and other selected individuals in their life that they would like to be involved. One of the features of person-centered planning is the use of graphics to illustrate things so people who aren't good readers can follow along and our pictures of these components are to give you a little sort of taste of how that looks.

Next slide is component three, career exploration and work experience. So that following the development of a person-centered plan people will need to explore and

get some experience of what they're interested in. That could include informational interviews, job shadowing, work experiences, a summer job or visiting colleges for people interested in post secondary education. Some could be in person and some people do some Internet research as well. And then lastly the fourth component is kind of embedded into number two and number three which is a peer mentor. Each of our sites we have a person with Asperger's syndrome who is a member of our project team who serves as a guide or mentor to the participants related to helping them plan their participation in meetings and in helping them organize their exploration and visits.

So next slide. It gives the project organization. We have a consumer advisory group composed of consumers and families and our research advisory group and at each site we have a coordinator, two planning facilitators, peer mentor and a data collection person.

Next slide. Eligibility basically is having any kind of ASD diagnosis and being in special education between the ages of 16 and 18 so we recruited a total of 49 people and then randomized them into two groups. The first group gets the intervention in year one. They're getting it now. And so that's a total of 25. And then the second group is going to get the intervention starting probably in October when the first group is finished and when the second round of data collection is finished so they will be basically a delayed entry group.

Next slide. The things we're looking at are a whole package of measures that relate to people being more effective at career planning. We're going to -- we collected -- we finished the first round of data collection. The second round would be around August and September. We are asking people the same questions that the national longitudinal transitional study asked about family and student expectations. I think you'll hear a little more about that MTLIS questions in the next presentation. We are looking at adaptive behavior through the assessment scale. We're looking at self-determination. We're using both the AHRQ inventory when possible and the American institute of research self-determination inventory. The AIR one can be done by proxy. We have some people that can't answer the questions themselves. They're we're asking measuring career maturity and we're looking at people's pre-and post IEPs that tracks the quality of the transition component of their IEP.

So next slide. We're also performing -- using also collecting autism diagnostic observation scale data as a little check on the diagnosis because we have people that have been diagnosed in all different ways, some by psychologists, psychiatrists and other medical doctors and the severity of autism will be a moderating variable and doing a qualitative study. Interviews to try to figure out how people are experiencing the process. What they feel works best or not so good and how the components might be tweaked in the future.

Okay, next slide. Our status right now is we have all our participants and the approval and all the data is collected for group one and all the group one parents have been

trained in New Hampshire and Maine and then the group one participants have all had at least two planning meetings. Sometimes as many as four. The number of meetings is not -- somewhat is individualized but between four and six per person before the exploration begins in a couple of weeks. And then just sort of us looking to the future. I thought it would be good to end with a little bit of vision of what we kind of are thinking about as how we kind of approach this and I have a reference here from this problems are not always problems article. It was kind of a little bit of a guide to us. I think what we really would like to do is not necessarily six people or wait until people get fixed but to find environments where people can be successful and supported and so when you go to the next slide it will be the last slide.

Some nice things that have happened in our project is one was -- one of our participants with a member of his robotics team at his high school. These are the people in the top picture on the right-hand side in the light blue shirts. He's one of those people and won the state robotics championship. You can see in the slide below their blue robots won the soccer game against the red robots and to me this is a good example of a situation where this young man's strengths are valued and utilized and his weakness, which would be kind of not too sophisticated in social behavior, is really unimportant in that group. And so that's it for me and I'll turn it back to you, Stella.

Thank you.

STELLA YU: Thank you, Dr. Hagner. At this time I want to remind our audience to consider submitting questions during the presentation and we will address all of the

questions at the end. Our next speaker is Dr. John Butterworth from the University of Massachusetts-Boston. Dr. Butterworth is the P.I. for secondary data analysis grants study services and outcomes for transition-age young adults with ASD. Dr. Butterworth is the coordinator of employment systems change and evaluation at the institute for community inclusion. He has over 30 years of experience as a manager of community-based day and employment services, trainer, consultant and researcher. Dr. Butterworth, I'll turn the program over to you.

JOHN BUTTERWORTH: Great, thank you. Our focus has been on analysis of two large national databases. First the national longitudinal transition study, a study currently in process, that is a restricted use database managed by the institute of education sciences and second the rehabilitation services administration, 9/11 database which is data collected at the point of closure from vocational rehabilitation services and if you could go to the next slide, please.

Program goals. We've been working our way through an analysis plan that began with descriptive data and better understanding particularly a database and figuring out some re-coating needs. Moving to more comparative kinds of analysis looking at people with ASD compared to some other populations, key populations and we're currently kind of in a phase of implementing the more predictive stage of our analysis. But our key project goals from an analysis point of view is to identify personal and programmatic factors that relate in key postsecondary outcomes. And with an intent of using that analysis to help inform design of transition services and supports.

Next slide, please. Just a simple kind of overview graphic of what we see as key domains we're working with. Clearly post secondary outcomes is what we're shooting to predict and understand better. Post secondary education, integrated employment outcomes as well as independent living status of young adults as they exit the school system. We're looking at that in relation to two other clusters of variables. The two databases we have do better jobs at one or the other of those. The NLTS2 is good at personal and family characteristics and has a broad aware of variables. Over 10,000, in fact.

It says that on the next slide. Focusing on demographics, health status, social supports, family expectations, pretty wide range of elements collected in multiple ways. And then the final domain is education and rehabilitation supports and services and that includes involvement in development of the IEP. It includes the actual employment and career experiences students have within the school system and the services they receive from the vocational rehabilitation systems.

Next slide. For the NLTS2 is a 10-year longitudinal study. The first data was collected in 2000 and 2001 that includes over 11,000 young adults who receive special education services and about a little over 800 of them are individuals with ASD. Over 500 local education agencies as well as some special schools and participants were age 13 to 16 at entry.

Next slide, please. This just gives a very brief overview of the data collection process. Down the left is a sense of the different sources of data, parent interviews and youth interviews are continued on a two-year cycle throughout the project. Some direct assessment two cycles of surveys of teachers, a couple of cycles of collecting descriptive data about the school programs and then a look at transcripts.

Next slide. I'm going to share just a few primarily descriptive, some comparative statistics. The first is primary post school goals as identified by -- this is from the teacher responses. I think what's striking about the post school goals to me is that the young adults with ASD were ranked as having some of these living independently in the community, only 30% of students with autism had that as a goal compared with over 60% for the three categories are students with ASD. Students with intellectual disabilities and everybody else. That's everybody else who had an IEP that was a participant in the study. For students with autism only 30% had a goal of living independently in the community. Only 26% compared to 60% of the general population in the study had a goal of competitive employment after high school. Only 23% compared to almost 60% of the general population had a goal of living in a two or four-year participating in a two or four-year college program and students with autism had the highest percent with a primary post school goal of working in a sheltered workshop, even higher than people with intellectual disabilities. Kind of a striking finding in terms of teacher expectations and the content of a student's education plan.

Next slide, please. The next slide looks at parent expectations, information collected directly from families. Again, students with autism tend to have very low levels of expectation compared to the other groups, including young adults with intellectual disabilities. Only 13% were expected by their parents to live away from home without supervision. Only 10% were expected to earn enough to support themselves. Only 46% were expected to have a paid job.

Next slide, please. So a couple of sample outcomes. And I think on a more positive side the differences between groups are less extreme as you begin to look at actual outcomes. So young adults with autism and this is young adults who have at this point exited the school system. This is from the latest phase of the surveys that are available. 66% of young adults with autism had worked for pay at some point since exiting high school compared to 90% of the more general population of study participants. 47% currently have a paid job. 42% had ever attended some form of post secondary education. A reasonably high percentage compared to only -- still only 56% for the general population of participants.

Next slide, please. And then a few things about the actual nature of those outcomes. People had been working for a relatively long time in most cases, particularly given that this is shortly after high school exit so an average of 14 months for young adults with autism. Young adults with autism tended to work fewer hours on average, about 29 and tended to have somewhat lower wages pretty close to the minimum wage with an average of \$7.87. Not in here is the sense of some of the services that young adults

got and I think what was striking was that they had a very high level of participation in occupational and vocational education in the school program, they conversely, despite having that as a primary focus, had very low levels of participation compared to other groups in things like career assessment and career counseling instruction and looking for jobs.

Next slide, please. The rehabilitation services administration database collects data on about 600,000 closures per year with a focus on individual characteristics. Services received and employment-related outcomes.

Next slide. Perhaps what is most striking is the change in participation of youth with autism or individuals identified as having autism in the database. It has grown to over 5,300 in 2008. A very striking change in number and engagement with the voc rehab system.

Next slide. About -- of those 5,300 young adults, about 3,300 developed and individual plan for employment. That's an IPE. About 2093 exited with an employment outcome. That's actually, if you go to the next slide again, rehabilitation rate is a key index used by the voc rehab system. That's actually a pretty high percent exiting into employment. Higher than either young adults with intellectual disabilities or the more general population of voc rehab participants. Young adults with autism did have, again, the lowest average hours per week and close to the lowest average earnings per week of all closures.

Next slide. And then finally services received, young adults with autism were much less likely to be receiving college or university services. Much less likely to be receiving focused occupational-specific occupational -- vocational training. Much more likely to be receiving direct on the job training services like job readiness training, job search, job placement or on the job support.

And you can go to the next slide and I'll pass it back to Stella. Thanks.

SELLA YU: Thank you, Dr. Butterworth. We're going to now transition to our two research networks. Our next speaker is Dr. Connie Kasari. She is a professor of psychological studies and education and psychiatry at UCLA where she is the P.I. for several multi-site research programs. A founding member of the autism research for 25 years. The current research focuses on developing targeted interventions for early social communication development in at-risk infants, toddlers and pre-schoolers with autism and peer relationships with school-aged children with autism. She's also involved in several randomized control. It is aimed at underserved and underrepresented children with autism. I'll turn the program over to you.

CONNIE KASARI: I'll talk a little bit about the autism intervention research network for behavioral health. It's a network of researchers from five institutions, UCLA, University of Washington, Kennedy Krieger Institute and Florida State and University of Michigan. Pretty well representing the country.

Next slide, please. We have three main activities. One is to develop research protocols. And dissemination and tool development.

Next slide. So we've so far developed several research protocols. These are really based on kind of our common interests and the needs of the community. So in the first one protocol one is a joint engagement intervention for parents and young children with autism. So one of the things that was recognized as happening was that a lot of families were not getting early intervention services and so we're trying to correct this in some way by having a home-based intervention for parent training with their young children. Protocol two concerns social skills interventions at school. And the third protocol is a new one that social skills via of a web-based delivery. I'll talk a little bit about each of these in turn.

So common features -- next slide, please. Common features of these protocols are that they're all focused on underserved or underrepresented populations. That really varies for the different sites. So in Los Angeles, for example, we're in neighborhoods or schools that don't have a lot of services. We've translated most of our protocols into both Korean and Spanish, although there are lots of other languages and -- but those are the two common ones. Our intervention focus is on core deficits in autism. We're focused on attention, social communication, language, social skills and not as much on some of the other concerns that are behavioral problems and so on. Our interventions are carried out in natural environments. So all of these interventions are based in

homes and in communities, or in schools. So we're not carrying out our interventions in the lab. And they're all multi-site studies so we've -- because of that and because of the geographical distance, we've developed a web-based online manuals for training and very collaborative treatment approaches which has been a really interesting process given the numbers of people we're involving.

Next slide, please. So in protocol one this is a joint engagement intervention and the problem is that children from low income environments have much less access to evidence-based interventions so for us the common thread for being underserved is low income. That varies, of course, across sites. So we're doing a randomized control trial where we're comparing parent education models to a parent-mediated intervention. The question is really can we deliver this information via just parent education? Is that as effective as actually working one-on-one with the family and a child in the home? The between the ages of 2 and 5 years of age and we're aiming to see 125 kids across our sites. The interventions are twice a week for 12 weeks in the home. A fairly short-term intervention but based on the national research council recommendations that we should see change in three months. Three-month chunks of time with kids with autism. The focus is on joint attention or joint engagement across everyday activities in the home. So that's going to be variable for various families and our outcomes are on social communication abilities and engagement and, of course, we're hoping for better language skills as well. So we made a number of changes just based on our pilot cases. So we've changed from once a week, which was the original design, to twice a week and we've reduced our numbers as a result of that. We also

had some huge challenges just in recruiting and maintaining schedules in these underserved populations so we were recognizing that we needed to have more of a relationship with families so changing from once a week to twice a week and then allowing ourselves enough time to get in these visits, since parents are fairly challenged. We have families losing homes and moving around and so not able to maintain those visits easily. So our progress at this point is that we're currently collecting data. We have weekly phone calls and for supervision, for fidelity, it's a pretty intensive effort to make sure that we're all on the same page and I think we've learned a lot about just that process in doing research. Our database is set up. We have a subcontract with SISTAT at UCLA. They take care of the randomization, screening, we input our measures by site so it is completely separate from any one particular site.

Next slide, please. So for protocol two, this study is really focused on kids in general education who have high-functioning autism and these are kids that are often without services and have a huge need for social skills interventions. And really represent another underserved population of kids. We're hoping to see about 150 children across this network. And we've developed two different models. One is an engage model that involves typical peers and involvement of typical peers in the child with autism on the playground. It is done at the school. This is a really unusual study in that most social skills treatments are not done in the natural environment. And we're comparing that engaged group with typical peers to a social skills group with standard practice. They have different disabilities and don't come from the same classroom. In this case we

had issues with recruitment and concerns in these particular neighborhoods. So the skills group is done at the school which is a little unusual because most social skills groups are done in clinics and off-campus. So both groups are in schools but they are different in that one involves typical peers and the other one is a more skills-based group.

Next slide, please. This is an example of our Peer Engagement Group, or the engaged treatment condition. So we have an online treatment manual that is accessible across all of our sites and the manual includes a lot of detail about the treatment. It has video samples. All of the measures. And it is a way that the different sites can upload video sessions. We can code fidelity and it is a way for us to communicate as a network and it is helping us conduct these interventions which are not particularly easy to do.

Next slide, please. This is an example of one of our outcome measures for this particular study. So it's based on some previous work done by the UCLA site in which we conducted a school-based intervention and one of our outcome measures was whether or not children who are high functioning with autism are more connected to their typical classmates. So this map demonstrates the connections between kids who play together at school. And in the upper left corner you can see that E5 is a child that's in red is a child with autism and when we first started the study, this child was isolated. None of the children identified the child as playing with other children on the playground. In this particular study after a few weeks, six weeks, 12 sessions, the child is now connected to a group and you can see E5 at the top in the right-hand corner

map. And when we come back in three months, at the bottom of the screen you'll see that E5 is still connected to a group. So the goal is really to get children with autism who are in regular classrooms connected to their classmates. And so based on that pilot data, which involved typical peers in the treatment, we're now trying to do this multi-site study.

Next slide, please. In protocol three, this really developed out of the interests of the network group. There was a problem that people saw in terms of available services for rural family and it reminds me of Susan Hepburn's study in terms of a lot of families just don't have access to services for children with autism and they're far from an autism center or medical school and so we have a group of the network working very hard on developing a web-based social skills treatment. The focus is going to be on rural children who have this limited access and most of this data collection will be done in rural Florida. And it has been an interesting process in that we are uploading assessment measures onto the web-based platform so there are measures for parents and for teachers and for children, and then there is a delivery of the social skills treatment in 14 sessions, which we can see if we go to the next slide.

An example of what this intervention will look like. So there is, you know, a private log-in and registry and we can log in how much time the child is spending on the lessons and that they moved through the lessons. So this one is still in the development phase but it is almost ready to launch and then all the data will be collected in rural Florida.

So next slide, please. So one of the goals of the AIR-B networks has been to leverage these collaborations we've developed and we've done that luckily with some of the ARRA funds that became available. The peer model we're doing in elementary schools was exciting and there was a huge need in middle schools and high schools so they took that idea and adapted it for high school kids and got NIH funding to do the same kind of thing in high schools and middle schools. So it's very interesting. We're calling it protocol four and we're also in an underserved group. This is an underserved group of children in Los Angeles who are all in title I schools so pretty diverse groups of kids and that particular protocol UCLA is starting our first groups right now so we're just in the beginning phases. Slide please. Another big area for the AIR-B network is the guideline development. So in our case RAND is leading the contract development network. They're experts in this area. They're developing really a parent and professional-based review of the intervention research for behavioral health. The literature searches are now complete and they're finishing up their data abstraction and analyses and they're expecting their report will be done at the end of this year and we actually have a face-to-face guideline development meeting in June, June 3 and 4 and it is at that point that the guidelines will be finalized so we're getting close to the end for this particular development project.

Next slide, please. Another goal of the AIR-B network is to develop tools. So we have a number of different measures that the group as a whole have put together. We have two that are pretty far along now. One is a pragmatic rating scale that Kennedy Krueger is taking the lead on. They've developed this measure. We've had ongoing

web-based training and being used in protocol two and protocol four so it's a really nice scale that people have been trying to develop for a number of years. We're getting a sense of whether we're getting changes in children's pragmatic ability based on any of our interventions for the social skills protocol. And then another measure is the playground observation and peer engagement. We've been trying to do very quick, live observation coding schemes for playgrounds at school. We've been having ongoing training for this measure as well. We have some -- we've actually published now this measure in a couple of different studies and we're going to be using it in protocol two with an adaptation of this measure for high school kids in protocol four. There are a couple more that people are trying to put together, so by the end of the network we should have a few more tools that hopefully can be exported.

Next slide, please. This is an example of some of our dissemination efforts, which is another big goal of the AIR-B network. We have a public website that continues to be developed and another effort is an online knowledge base so kind of like a Wikipedia so that lots and lots of information is being collected on different kinds of interventions for autism spectrum disorders. That's an ongoing effort that we have the prototype together and our online manuals which we hope we'll be able to export with some password protection.

Next slide, please. So in terms of the future, we are just, you know, pretty heavily into recruitment and data collection right now but we're expecting to step that up over the next year. This is a huge effort to pull together five different sites getting IRB all taken

care of and everyone doing the same kinds of interventions. But, you know, now that we're going, you know, we're hoping that we'll get all of our data collected within the next year and have our results ready to share. We're also continuing to test our tool development along with our data collection. We should complete our guideline development this year. We're hoping to launch these web-based dissemination efforts this year and we're hoping to leverage these collaborations into new projects and one of the exciting things about these networks is that everyone gets very excited over new things that we're doing together and new ideas so, you know, that's a huge goal for the future.

Next slide, please. And this is our group of collaborators. There are a number of people at UCLA, which includes our SISTAT group. We have Florida state, Amy Wetherby and who coordinator. Robyn Schulhof. Bekka Landa and her coordinators. University of Washington is Brian King and all of our coordinators. Thank you very much.

STELLA YU: Thank you, Dr. Kasari. At this time I would like to urge you to submit questions again to our very distinguished panelists. It is very rare that we can gather that many people together in one program and really, you know, the value of life program is some of the discussions that can occur. So we hope we've got a little questions at the end of the program. Our next speaker is Dr. James Perrin for the intervention research network on physical health. A professor of pediatrics and Harvard medical school and the MGH Center for child and adolescent health policy

and associate chair of pediatrics for research at mass general hospital for children. He's chaired many national work groups and committees including one for the academy of pediatrics and the Institute of Medicine and he was the founding editor of "academic pediatrics" which was formerly known as ambulatory pediatrics. This is an abbreviated description of his accomplishments.

JAMES PERRIN: Thank you for the lovely introduction and the opportunity to share the work we're doing and excited about with the Autism Intervention Research Network on Physical Health.

If I can have the next slide, please. The goals that we have within the autism treatment network and the AIR-P network which we've built on top of the existing autism treatment network are four. One is to improve the quality of medical care that children in adolescence with autism receive. Second is to develop, implement and refine a model of coordinated care for children that adheres to the philosophy of the chronic care models. Third is to advance the evidence-base and research on medical issues to provide families with better answers to the questions they raise about caring for their children. And fourth is to become the leading clinical network on medical issues relating to autism spectrum disorders by developing and disseminating guidelines for medical care.

Next slide, please. The AIR-P program is funded by a grant from the Maternal and Child Health Bureau and its goals really are to build out the research component of the

autism treatment network to conduct research and physical health aspects of autism spectrum disorders as well as to develop evidence-based guidelines for the care of children with autism and provide community education. The AIR-P utilizes the infrastructure of the autism treatment network to carry out its projects.

Next slide, please. Connie was talking about five sites. We have gone through the process of IRB approval in 14 sites and it is always quite amazing that it does work. We have 14 sites in the United States including one in Canada, to be a member of the autism treatment network sites must agree to have a multidisciplinary team care strategy. They must agree to use the autism treatment network clinical evaluation which is a fairly complex battery of tests that we use for children and their families. They must agree to enter at least 100 subjects per year into a common registry and they must have staff who will participate in autism treatment network committees such as operations or some of our clinical subspecialty committees like the gastroenterology group or the neurology group, etc. Our key collaborators in making the AIR-P work is Autism Speaks, which actually provides the financial infrastructure for the autism treatment network and our colleagues are based in the Autism Speaks Los Angeles office primarily Nancy Jones and Claire. The clinical coordinating center that we run here at the Massachusetts general hospital for children includes a number of wonderful staff. I want to point to Dan Corey, the medical director of the autism treatment network and for the AIR-P as well and has been an extraordinarily great colleague here with us. The EMMES Corporation, our data coordinating center provides a lot of statistical and data collection backup for us. And with the support of the AIR-P program we were able

to initiate a good and strong collaboration with the national initiative for children's healthcare quality which allows us to go quickly in the area of clinical guideline development and implementation.

Next slide, please. This map shows you where our current 14 sites are. They are pretty well spread out across the United States and as I said before, one also in Toronto.

Next slide, please. I'm going to talk now about four areas of accomplishments of the autism intervention research network in research, in guideline development and implementation. In the use of our registry and in dissemination and community outreach.

Next slide, please. We've had a very active time in developing research protocol-driven research in areas relating to the clinical care of children with autism. So these are projects different from the AIR-B research activities. Hopefully highly complementary in the kinds of answers that we will get. The two projects we really began with, one is an extensive project trying to document diet and nutrition in children with autism. This is led by Susan Hyman at the University of Rochester and there are four other sites in the AIR-P that are part of this particular project. This will provide the first systematic, very carefully-designed study of about 450 children with autism to really describe in detail what kind of nutrition they're actually getting, how much they have the likelihood of being undernourished or have lacks in certain chemicals or are they getting over nourished in a variety of ways including the use of supplemental diets so we'll have a

great deal of information coming from this project fairly soon at this point. We're well into data collection here and it is really going very well. The second project we began with is led by Dr. Beth Malow at Vanderbilt University and this is really a controlled trial of a couple of different ways of providing sleep, hygiene interventions with parent training and strategies based on pilot work that shows you can train parents to change their children's sleep behaviors effectively. We're in the midst of this trial to see what seems to work best and we're quite excited about that project.

As part of the AIR-P strategy, next slide, please. We have begun an internal request for proposals so that we develop new research subcontracts with participating sites and we've gone through a pretty formal process of setting out a request for proposal, having people respond to that request with pretty well-developed research proposals and we've generally labeled these as level one and level two. I'll describe that again in a few minutes but based on our first request for proposals, when we got 16 applications, we were able to fund four very interesting projects which I'll describe very briefly. One is with Suzanne Goldman at Vanderbilt. She's looking at the data available through the AIR-P to define the relationship of sleep disturbance to psychiatric comorbidity. There is a significant rate of that in children who don't sleep well and this is a way of trying to get more systematic information and also to get more effective numbers than we've had in the past. Anne new Meyer at the family hospital for children is leading a study, a pilot study, bone mineral density in children. Male preadolescent children with autism spectrum disorder. There is a lot of interest in this issue of the relationship of the number of hormones that are indicated in children with autism and

bone mineral density. We'll get interesting data that might lead into some opportunities for changing treatment over time. Andrea Schultz at the hospital for sick children in Toronto and a group of other people in two or three other sites are working on understanding more about how important CREATINE deficiency syndromes are in children with autism. This has indicated and this is the first systematic approach to identifying filing how much of a problem it is. What are the indicators of that in this population and therefore who are the kids that we might want to try to treat as a way of improving their clinical status? A fourth study which is in many respects complementary to the diet and nutrition study I described a few minutes ago, Anne Reynolds at the University of Colorado is doing a systematic approach to understanding more about the metabolism of iron, whether it's abnormal or whether children with autism have abnormal iron status and this will be again a very nice study that will show some answers there.

Next slide, please. In January we sent around our second within network request for proposals. Again, for pilot subcontracts on treatments affecting autism. Submissions were due two or three weeks ago. We got 12 very interesting applications. We have sent them out for review. That's where they are at the moment. They're pretty varied. They go from EEG studies to studies of inflammation in the brain and what are some markers of that that might have some implications for treatment. I think a number of interesting projects are under review. I couldn't begin to tell you which ones are likely to be funded but we believe we're likely to end up funding another four or five research projects through this process. As I mentioned before, we have two levels of projects.

Level one are small starter pilot opportunities that are directed primarily to junior investigators wanting to get some early data and we support the upper level of \$40,000 in direct costs for one year. Level two projects are larger pilot studies we hope will gather preliminary data to support more extensive research projects funded from other sources. These projects allow up to \$150,000 a year up to two years. They must involve more than one center to be considered. That's the sort of update where we are on our research activities. A lot going on, interesting questions.

Next slide, please. We also have been very much involved in the development of clinical algorithms. The area of constipation, insomnia, night wakings and the use of electroencephalograms receive low gram. Medication monitoring, medication choice, the use of MRIs, the work-up by genetics and metabolics and behavioral toolkit are in development.

Next slide please: The constipation algorithm is the most developed that we have. It was led by the University of Arkansas. NICHQ has been involved in this, pilot implementation has been in Cincinnati, Colorado, now to moving Rochester and Arkansas. We are developing a toolkit for the constipation algorithm and these are some pieces very much in development now.

Next slide, please. Our insomnia night wakings algorithm developed by the sleep committee, very much involvement of NICHQ. Pilot implementation at Kaiser opened in California and Missouri expanding out to Baylor and Oregon. We've developed toolkits

and behavioral pamphlets for parents to help them know what to do about bedtime routines and we hope this will again result in improvement in care.

Next slide. Third algorithm relates to the use of electroencephalograms receive low grams in the evaluation of children with autism and will be piloted at Columbia and Massachusetts general in the summer or fall.

Next slide, please. Let me tell you a little bit about our ATN registry. This is what I mentioned before that each site to participate in the ATN is required to enter a number of children, 100 is the expectation, per year, in the -- in this data registry. As of the data that were available as of the early part of September of 2009 we had about 1,420 participants in the registry as of later in December we were up to 1800 and I believe we're now up to 2200 or 2300 children and adolescents in our registry. The first round of our annual follow-up visits, we had sort of year one visits, now the year two visits begin in May 2009 and we've had a recent meeting of a number of experts and members of our group to assess and revise our database. I'll tell you in a few minutes about some of the outputs from that registry but we have been very successful in using the data through that registry to answer a number of interesting questions about the symptoms and illnesses that children with autism have.

Next slide, please. The fourth area I wanted to mention briefly is our work in community and family outreach. There have been presentations now at four conferences that target communities and families at the Thompson center at Missouri,

the Kennedy Krieger Institute, the northwest autism center in Spokane, Washington, Xavier University in Cincinnati. Presentations of two medical conferences, medical University of South Carolina, American Academy of Pediatrics section on integrated medicine in Washington There are a number of other ones that we haven't listed here that have taken place since we developed these slides. We're very active in these efforts and we also have a web system that provides more and more information to families wanting to know more about what is happening in the medical care of children with autism.

The next few slides I'll show you are not ones I want to go over in detail but want to give you a frame of how much we've been able to do in the sense of getting publications and abstracts in this past year's time. We're really very pleased with the productivity of our group.

If I can have the next slide here are four papers. One that I did jointly with some colleagues at the CDC and led by Mike at the Maternal and Child Health Bureau about the -- some of the interesting issues of the changing prevalence of parent-reported diagnosis of autism in the United States both showing -- continuing increases in the frequency to which parents report this diagnosis among their children but also importantly talking something about children who apparently had the label of autism in the past but didn't have it now and showing some very important racial and ethnic differences in those populations that are very important for us to follow up on. A couple

of other papers are more review papers from Dan, a very nice paper from Karen based on children in the AIR-P network.

Next slide, please. These are examples of abstracts that have been accepted for the May 2010 meetings of the Pediatric Academic Societies.

Next slide, please. These are now abstracts that have been accepted for the IMFAR in meetings May of 2010. A point I would like to make here is both of these groups a good deal of the information that is available from our registry has been carefully analyzed to try to answer some questions such as the relationship of sleep disorder with behavioral problems in children with autism. Just rates of the use of psychotropic medications of children in autism. The of frequency of GI symptoms among children with autism -- so we're really delighted that we have the registry available to help us do these sorts of things.

Next slide, please. Here now are two more abstracts for other meetings for the meetings, these are again in process and we'll be turning these into manuscripts for submission and trying to get the word out about how much we're learning about clinical aspects of life with children with autism.

The next and last slide, please. In summary, the Autism Intervention Research Network on Physical Health has been very active, very busy and we have a wonderful team throughout the country really working together, about 125 or 130 clinicians and

scientists who are really collaborating very actively in this network. We're very excited about it. It's an active and productive network with our emphasis really as I said before on quality improvement and on improving access to children, a very active research program. An active and changing dynamic registry and active efforts to improve outreach to several communities that we're working with. Thank you very much.

STELLA YU: Thank you, Dr. Perrin. We've been working like clockwork. We're one minute ahead of schedule. We have five presenters. We'll start our Q and A session now. I would like to start by addressing a question to Dr. Kasari by asking about, can you share some thoughts on the general needs of underserved children with ASD with some particular thoughts on, you know, racial, ethnic differences? I know you've been working a lot in this area.

>> Sure. I think that that's the -- to us that's the reason for having this network. We've -  
- the five sites that are involved in therapy have all been active autism intervention researchers but we tend to see more advantaged patients who come to a large autism center and most of us have been trying very hard to get more representative samples. It's very difficult to do. The AIR-B has allowed us to go further out into our neighborhoods and network in other ways and I think all of us are trying to address whatever the needs are in our particular community. But what is interesting is that the common thread for these five sites has to be low income because of the variability in the geographical locations. So, for example, in Florida there is a lot of very poor rural families, or rural families without access so those aren't necessarily the same thing. In

Los Angeles, where we have just such diversity and as I was saying before we've translated all of our protocols into Korean and Spanish which tend to be the most common groups that we have access to. But there are other families and luckily we have a number of interventionists and professionals who speak these various languages. It's very important. This platform has really allowed us to, you know, try to actually provide services to families that don't have access. Did you want more?

>> Thank you. I will now turn over the program to Sue Lynn will who moderate the next few questions.

>> Hello, we're thrilled to have hosted this webcast this afternoon and have some questions that have been committed through the messaging center. And we still encourage you to submit to the messaging center if you have any questions for our speakers. Let me direct the first question to Dr. Hepburn. You had spoken of anecdotal feedback on the videoconferencing therapy with respect to gestures and eye contact. Can you talk a little bit about how you'll be capturing and collecting data on the feasibility of this modality of therapy?

>> That's an excellent question. What we're trying to do to look at feasibility is we're keeping a log of technical difficulties so that we can see when audio or visuals have been problematic. We're looking at factors like attention and participation. Are the kids and their parents predicatively joining the sessions that we have scheduled? We're also asking them to complete satisfaction measures at pre-determined points looking

at the quality of the therapeutic alliance as well as whether or not they've found the technology to be easy or hard to use. And we're gathering a lot of qualitative data as well as the ratings that they'll provide. We are going to be recording -- you can actually film these sessions and some of our research staff are also going to be recording some of the non-verbal behaviors of the kids themselves during the session so that we can have some kind of an index through an integral recording system to see if they're attending and actively engaging or if they're distracted and doing other thing. So it will be a combination of behavioral observation, report by the parents, report by the kids and our own logging of what goes on as we try to deliver these interventions.

>> Great, thank you so much. Dr. Hepburn. The second question that we have is for Dr. Hagner. You presented that the eligibility of the subject pool included any of the youth age 16 to 18 with any ASD diagnosis. Can you talk more about how this may impact the measures such as family, expectation and self-determination?

>> Sure. Obviously we expect people more higher functioning will have higher expectations and their parents will have higher expectations but we're measuring people's own pre-post measures, not compare people one to another and we're also using a level of severity as a moderating variable. We expect that kind of thing that it will be varied. We were surprised we got an amazing response to our recruitment because, you know, autism being somewhat of a -- it's more common than it used to be but still somewhat of a rare diagnosis and mainly New Hampshire not being hugely populated states we were worried if we limited it to a particular level of ASD we would

have trouble getting sufficient numbers. We turned out that probably wasn't true but so now we know. But we bring people from whatever level of functioning. Some people are non-verbal and those individuals probably will not go to college. Certainly still can plan an integrated job in the community. We have other people who -- one of their biggest issues will be social relationships at college, picking the right major and that kind of thing and we have -- I think we can help people really at any point on the spectrum.

>> Thank you, Dr. Hagner. Here is another question for Dr. Kasari. How long did it take to develop the research protocol number two and how long did it take to set up the network?

>> I had to un-mute me, sorry. So for protocol two, which is the school-based network. The protocol itself we had a Head Start on because we had been doing some of this at UCLA. So the -- and so the engage protocol is from UCLA but the skills protocol was developed by Seattle so it is really a combination. What takes a very long time is getting through IRB and getting into schools. So actually working with schools and getting in is difficult. Even if we have -- I've had a relationship with the school districts here for a long time, it is still quite a large process. Once you get in, of course, they never want you to leave. But it's that process and setting that up, that's, you know, it's taken time. It took -- we in terms of training the other sides, we've done videoconferencing, we've gone to the different sites and we've had face-to-face group

meetings. So it's several months process to even feel that the protocols are, you know, ready to launch. I think there was another question, protocol two. I'm not sure.

>> Would you like me to read it? A question regarding how long did it take to set up the network.

>> Right, we had the network of investigators, of course, in terms of setting up the protocol and training and all it is -- because of changes we made, probably a year. A year to get everything going. So we've just finished, I think, three cohorts at UCLA. But another issue with school-based treatment is schools are on a school calendar and so that also adds more constraints than, say, going into a home which you could do year round. So summertime a lot of times schools are off. So depends on the location. In Los Angeles, we've got tracked schools. Some schools still go in the summer.

>> Thank you so much. The next question is for Dr. Butterworth. The descriptive statistics around post school goals and parent expectations have somewhat of a similar pattern in looking at the ASD, ID and other groups, does the youth interview also demonstrate a similar pattern of transition to adult expectations on the youth end?

>> That's a good question. I'm not sure I can pull that off the top of my head but let me see if I can pull some information up quickly. I mean, I think in some of the past data I've looked at to part of what strikes me is that youth tend to have higher expectations than most other groups. In fact, on the employment side they tend to say kind of

across the board that they expect to be engaged in employment. So I think it tends to trend higher. I'm sorry, I can't put my fingers on the actual numbers. I'm not sure I can answer whether or not that's a similar pattern off the top of my head.

>> That's fine. We'll follow up with them, Dr. Butterworth in the future. One final question that we do want to take now is for Dr. Jim Perrin. And it is to inquire about your vision into the future of autism research. Dr. Perrin.

>> That's a very broad question but I can try a couple things. I think that we're very much on the cusp of a lot of new information about autism. I think we're going to learn a great deal more about the genetics of autism, a great deal more about the metabolic and underlying physiologic and brain chemistry issues in autism but importantly I think we'll also be very much on the cusp of translating a lot of that new knowledge into new treatment options for autism. So my vision really is to think about where we were with childhood leukemia 35 years ago and to recognize that at that time parents were trying all sorts of unusual treatments because we had very little to offer them. We would usually tell the parent that your child will likely survive, will get better for a little while but then she is going to likely have a fatal outcome from leukemia. What happened was a lot of people across the country got together and said we can't do this by ourselves but working together we can systematically try new treatments and as I think you all know, today children with leukemia have about a 90% survival rate, maybe a little higher than that. Sometimes with less than perfect outcomes and we're working on making those outcomes better but it is a vastly different world because people were

willing to collaborate and do new trials and therapies. That's where we are now with autism. I hope by working together across the country we're going to be able to really bring about major changes in the quality of care for children.

>> Thank you, Dr. Perrin. Let me turn it back over to Stella.

STELLA YU: Yes, thank you. I want to just, you know, say a couple of things to thank everybody about joining our program today and I want to thank the speakers and the autism team at MCHB. We've covered a lot of information and hope you will continue to follow the progress of our innovative projects and invite you to consider submitting proposals to the MCHB autism program. If you have a particular interest in following up with any one of our speakers, you can access their information by going to our website, [www.hrsa.gov/autism](http://www.hrsa.gov/autism). Thank you for joining today's program.