ASD Advisory Committee Evidence-Based Treatment Workgroup 11/4/15

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There was a clear recommendation that there is no distinction made b/w rehab and hab

From a clinical perspective I definitely agree that this distinction is arbitrary - from a legal and Medicaid/CMS perspective were are still evaluating whether or not we need to make such distinction- we are having conversation with our legal team

I thought we had a clarity that there wasn't going to be a distinction

So recommendation is not to make a distinction b/w rehab and hab services (agreement)

This will need to be changed in multiple places – rules, policies, etc. Must be in compliance with federal requirements.

As far as the DDD acute plan what have been doing as a trial is trying to get a sense of the situation — for kids who are in DDD, if I'm getting this request, I'm finding that half of the time DDD already has authorized it to them. Some of the time they haven't. What I said as a recommendation is that I feel like the health plans should be the hub for that…just send it to one place. Ask the health plan to take care of it b/c DDD is not set up for prior authorization and it causes confusion.

We talked about simplifying systems- so the child may be referred to AzEIP…. And AzEIP decides that to recommend the therapy (PT, ST, feeding, etc.) - the request would go to the health plan, then it's send to the PCP to sign off on it and if it's medically necessary they are going to send it back to the health plan to authorize it. So that is how that process works. So only If the health plan doesn't authorize it would AzEIP pick up the cost of it. This process is similar to a private health insurance.

AzEIP would pick up the cost of services the health plan does not deem necessary. It doesn't happen w/ our plan but it happens a lot. Under the federal rule Medicaid is primarily the last funder but under rule 3 AzEIP is the last funder.

Talking about the chart-there seems to be a lot of concern about the chart-do we need the chart? And if we do should we do all the funding?

This is not the topic for this workgroup

The chart is intended to be internal and not external for others as stated in the email – it's a way to help the workgroups get a handle on coverage

It would be helpful for this work group to look at what other states have done in terms of a minimum amount of things that a child/person w/ ASD can get…and make sure that on the chart distributed that we are not missing anything

I think we have covered the hab and rehab clarification- I just wanted to know if there are any other topics re evidence-based treatment that you want to bring up before we move into clarifications re workgroup recommendations.

We have been talking in previous meetings about putting together a possible check list for pediatricians to make sure that they check for comorbid conditions- and b/c ASD is ever changing we talked about having a committee that would meet on a yearly basis to review new research and see if we are going to change our matrix re treatments. But we were stuck w/ who this committee would report to - we agreed that we would have professionals with various expertise such pediatricians and some parents on that committee - someone gave me this idea SMAC [State Medicaid Advisory Committee] is a group that we can report our findings to. Would that be appropriate?

We don't have the technical expertise at that meeting although I guess it could be a forum. Going back just a step around the big picture…I'm always about streamlining approaches. So does this group feel that there wasn't a report at a national level committee reviewing evidence-based treatment and research that could be used in Arizona?

It does happen on a national level, but we wanted to make sure that it was current and what we needed in the state

So you feel like it's not timely on the national front?

Didn't we have a list all of the things that PCPs should be cognizant of for ASD in the AAP?

I found some older documents

I though you found some documents/recommendations for primary care doctors?

Yes I did

Overall, there was a concern that the national studies did not present a comprehensive, unbiased overview of the current research – that led to the workgroup developing this matrix

Ideas that have come under discussion that could be a recommendation - using a matrix showing the latest studies, classification of treatment—evidence-based vs. emerging treatment vs. experimental treatment--having that matrix available; Creating a committee w/ multidisciplinary licensed professionals and a few family members to update the matrix annually; Improving communications to all families for all services; and design and implement a consistent process for ongoing evaluation for treatment results in improvement.

I think when it comes to the committee, one person gave an example of a treatment that later on became the standard of care- so maybe something that is considered as anecdotal this year can become standard of treatment next year w/ the publication of research- we want make sure that we don't wait ten years.

I agree w/ that approach, the question is we never want to reinvent the wheel-we want to leverage currently existing structures- so the question is, is there a national body right now that regularly meets and actually is reviewing the evidence?

There are several committees/entities that have done scientific review of lit. Some of these entities are highly represented by ABA-that is good but that is also potentially confusing-what we want to do is look at all the large systematic reviews and than put them together side-by-side and that gives us the most up-to-date information

Is it Impact on behalf of CMS, National Standards Projects from National Autism Center, Vanderbilt evidence-based practice; Stanford ASD research team (START)?

START was not include in that b/c they only did a certain group of them

We did four - CMS/IMPAQ (2010), NSP2 (2014), NCPD (2014), AHRQ (2014)

All of the things you are talking about re best practices are for treatment of ASD itself; the AAP also has guidelines and best practices for pediatricians; AHCCCS delegates to the health plans to look at new technologies/ new innovations. Just b/c something is experimental certainly you come to health plan and I can look at it…and look at all the lit. That's my job as medical director.. and say this looks experimental and deny it… the doctor can call me and argue about that, the member can appeal that, people can provide evidence that this is becoming a standard of care. I just want to emphasize that we look at beyond what is currently experimental today-there are processes in the health plan that are working right.

The problem is many children are not get the services b/c they are deemed experimental. What I don't want to see is that we spend 10 years claiming something is experimental-I want this to be ever evolving

There is a wide consensus that there is no one place to go that seems to be an independent unbiased look at how things are classified, which was the reason why Terry took on developing this matrix. And it needs to be updated annually.

We don't want to be in the business of telling people you have to do or use this treatment for your child - if a family has tried one and it has not been working- and they have tried something on their own and said that this is working-and then we do some review of it- and it really looks like it's emerging evidence- we just don't want to rely on this committee saying no you can't to that.

I understand your concerns. There was never an intention that the committee would rule out anything or get in the way of the medical director's role. Rather, we wanted to take an organized look at how treatments are being classified.

To be fair denial has never come from the health plan- it's DDD or RBHAs

ASD is multifaceted- I think a lot times people fixate on the behavior instead of looking at the medical side- it involves many professionals working together to deliver treatment-e.g. PT, ST, behavioral, medical. I don't know if there is a body in the US that looks at lit., of all these categories-and gives a report.

And this is based on behavioral interventions?

It wasn't just behavioral it also includes medical.

California has looked at the best practices not only for treatment but assessment and medical care- we looked at different states that have included some of those things- we are looking at treatment aspect of it b/c our workgroup is in charge of the treatment aspect of it.

The other piece of it is how do you document whether or not this is working –what is your treatment integrity?

We are not doing an updated plan for CMS- state plan amendment-so we looked at other state plan amendments. They got very detailed about those re treatment.

What we want to avoid is to say we have drawn the line and we wait for another ten years before we draw the next line. The other issue is making sure professionals are documenting how they are doing their treatment integrity-so if something is not working, how do we make the decision so that we move to something else.

In New Mexico providers were not doing a good job documenting treatment- we need make sure that doesn't happen.

I think this where the field has gone but this not necessarily what's happening on the ground for families. So if we say these are the treatments but if you are not getting those treatments in that way- then it doesn't matter

So what would your recommendation be around this?

When we look at SPAs several have put specifics about how they are going to measure change -they were specifically talking about you need identify what measures of change that you are going to use— how are you going to include the families- we could visit some of the measures-but we have to decide how much details we are going to put in our recommendation.

Who is going to do this?

You have include those measures in your treatment plans

What supposed to happen is –every three months there is an assessment of how we are doing –review what goals we have-what new goals we have- that is supposed to go to my pediatrician-so when he/she writes a script he/she should be thinking I wrote a script for the last five years for speech-I am a really seeing improvement? I like to think about OT - my son did 10 years of OT-and we really had no improvement- if we had something more data-driven, we could have realized half way through his treatment that this is not money well spent

I think we want to be as specific as we can- but also recognizing that we have different players-what our outcomes look like are going to be different from DDD's outcomes which might be different for Behavioral Health. But the key thing (and implementation science has been clear on this) is that what we need to do is say here is the outcome here. This is what we have to measure-and at least quarterly we are reporting some data that matters whether or not there is change.

I like that idea- that make sure we keep the PCP in the plan -in the loop -and also not just the treatment part but also the surveillance- doing all the things that we recommended in the article- any resources that we can find that says these are the things that you were taught/trained in as a PCP-you need monitor this for a child you are managing who has ASD. Please remember to consider all of these listed things-and monitor those things over time

The concern is real about the blinders-that a child presents having an ASD- and we just let the blinders come on-and we focus on behavior- but there are all of these other things that might be in play

Regardless of what group it is-this should be part of what they should be doing

I would like to add I was lucky enough to sit in on a team- a kid was getting ABA- b/c the team was meeting they noticed the kid was gaining skills and losing skills-they made a recommendation for the kid to see neurologist- the child was having 36 seizures a day and nobody knew it-so it's important that we talk about what are we paying for-we should include people meeting with each other and having conversations about the treatment plan so that we are getting the biggest bang for our buck

This one of the problems I struggled w/ as a health plan medical director over the years-looking at therapy-

Each kid is different-based on how they are responding- over the years-looking at the request for therapies-have they been checked by a neurologist-they are not moving one side of their body- the problem is we get what we get at the health plans-unfortunately what people are viewing as denials by health plans from my stand point is us trying to get information to move forward- I found it doesn't work very well. We are seeing some of the blinders-but nobody is looking at the whole picture.

The other thing is the perception that there will not be improvement-preventing regression-but actually there might be improvement-if you have a change of venue of what is being offered.

DDD actually started requiring providers to bill our private insurance-the quality of services improved-b/c they had to answer to our private medical plan-and the reporting that the private medical plan required was higher reporting than DDD –I was talking to the other group about recommendations to move services to the acute care plan- this will improve the accountability b/c they operate like private health plan-they are not doing different from others

Does private health plans pay for care coordination?

Not in Arizona.

Not sure if I can answer that… there is a bunch of work being done through AAP w/ respect to care coordination and value based purchasing

In terms of what we do with DDD and care coordination- so that we don't have the speech therapists only looking through speech therapy lens- having a person's job be care coordination rather than what we do in AzEIP is we pay for what you are talking about – we pay for that team to come together- so that the speech therapist doesn't only look through speech therapy lens – the place we would like to get better at is including those behavioral health providers when the individual is receiving those services. And that we pay our people as well so that they could have that conversation w/ the physician-so that they can include them and update them

Are we looking when we are thinking of evidence-based treatment w/ care coordination- there many different types of it- if you have the right types-the research that I have seen shows care coordination embedded in primary care clinics- if you have the right type of person for a child- some people in our State are doing including-Dr. Letizia [has care coordinators]-it means nobody is sending something to deny-which means they are doing something right. The other care coordination model involves health plans-and you have this idea that you have behavioral and physical health co-location

This is why it is important that we define the term care coordination

The other workgroups are talking about re recommendations for care coordination- not endorsing one specific model-but listing aspect that should include in care coordination

Some children with ASD need three hours of speech-but maybe they don't need PT-I just want make sure that we don't make recommendation that don't give flexibility for us to decide what is the biggest bang for the buck

I think we have issues w/ PCP education & educating parents

I agree

That is something that has come up in some of the other work groups

What we have heard so far:

The adoption of the Trailer Bill language and concept of evidence-based approach

Having and maintaining a matrix on annual basis, is this something that you want to recommend?

Designing and implementing a consistent process with respect to evaluation, treatment, documentation, and integrity.

Improving communication for family about all services available to them

Is there a consensus on this?

Yes.

Can the communications go into Don's communication plan?

Yes.

One state that we researching- the treatments had to be chosen based on the child's needs-I think having some kind of language around that is important-b/c we don't want people to say I want all of the treatments listed

I think our definition for evidence-based encompasses such language- our definition states that best professional expertise combined w/ individual characteristics, that becomes a quality assurance issue-

Is there a way we can reward physicians for adopting this approach?

This would go back the value based purchasing-one recommendation can be that you encourage the health plans to implement value based purchasing for good systems/good outcomes.

It takes more time to do care coordination-I have more time with a child w/ disability-that extra time is b/c they understand it takes more time-and nobody was paying them-so think about how do we do value based purchasing so that we reward them for doing that-having care coordination/care coordinators.

I think having that as a recommendation is really good.

One of the problems with medical homes for kids vs. adults-it's easier to look for outcomes for adults vs. kids b/c there always has been an issue.

For birth to three program we have been measuring all children that come in into early intervention-social relationships-appropriate behaviors-there are metrics I think that they could use

How does a health plan develop value based purchasing model? And what core measures would they use to provide the additional funding for the pediatrician like that? That is the difficult part

The child outcome- we are talking about a group of kids where moving the needle is tougher

The other piece is measuring the family centeredness of the program (and there are lots of metrics for family centeredness of the practice)– Family Voices is the place

I'm wondering if we can encourage more family training-most programs, train "habilitaters" – the issue is we have turnover problems-so we are constantly paying to train transient people-if we train the parents first, the parents can train transient people –also when we train parents they can push it in all sorts of environments that a professional cannot do-if I see speech therapist one time a week how is that going to help if I'm not involved in that process-In dealing w/ families I see some families who are very involved and others that are completely disconnected it would be nice to find a way to encourage more parent engagement

How would you phrase that as a recommendation?

Maybe the professionals here can help phrase it

What services exactly are you talking about?

I understand what you are saying- I think we are talking about some of therapies- PT, ST, OT-one of things we can start working on is a giving families a home program earlier

Some of the research is looking at intervention aimed at the child vs. parent (so that parent can learn the intervention)-parent interventions will impact child-more intensive-everyday at home

Are these behavioral focused therapies?

Not just behavioral. But thinking beyond that…the phrase that we would use is capacity building- the focus of intervention on the adult in the child's life-how do we ensure that professionals help train the parent-sometimes we get into the schism of we want the parent to become a therapist-none of us are saying that parent needs to become a therapist. We want to build the capacity of parents to be that constant for that child. We are doing a disservice if families think that 1 hour of speech or 2 hours of OT is all their child needs.

Re physical outlay of the clinic- is the room big enough to include parents? Is there a window where parent can observe? And the attitude of the provider-is the parent welcome?

The type of therapy is what defines the kind of space the provider uses- larger space vs. smaller space

So would the recommendation be making sure that there is a parent/family focus and making sure that there is a capacity building for parents?

Is that more like the model? Are we drifting away from our focus on the evidence?

No. I think you look at Minnesota. There is a piece in every treatment plan that states how are you going to develop this parent's capacity? You can do whatever intervention you want to do-but what also are you going to do for the parent.

We can definitely do that

I think it has to be a philosophy from the top. People who are leading the program that they reinforce that and that they help grow that.

It all has to do with who pays the bill- and whether or not in order if you have to be paid you are going to this…

The DDD policy manual-includes having parents participate in therapy-if you are not in the room there has to be a window you can see in-and I can tell you that doesn't happen in clinics

I think that is a good point-we should may include that as part of our conceptualization of what evidence-based practice is…maybe we add another sphere that talks about building family capacity and not just about treatment.

I feel very passionate about that-no matter what professionals are working w/ your kid-when they turn 26 they are on your couch - a lot of times families don't understand that-they delegate the power to all of these experts- I think we need change that attitude.

They almost feel like they are lost-now what do I do?

They talked about the cliff at 22 – and what happened to families when school funded services ended-and they have to figure it out-I think the point is important about how do we help parents w/ capacity building-and help the understand that this is your life and your child's life.

I think you should include the word transition in this plan- transition planning

The adults w/ ASD workgroup is talking about this.

The division for exceptional children talk about the transition from hospitals to early intervention- from early intervention to school-school to adulthood.

Most people think transition starts at 16 not even 14-but you have to start earlier to get there

Re transition areas is also from pediatric system to adult care

The adult transition work group is also covering this topic.

A lot of phone calls from low-income families-they don't have basic parenting skills-sometimes they struggle with just being a parent- sometimes CPS has already removed the kid-and they need a parenting course - sometimes ASD United will give them a free scholarship for parenting courses- I don't know about any resources for parenting classes-do we know if we provide that?

Parent management training-this provided through the RBHAs- if we had an integrated health plan for ASD-more parents would know about it.

The home visiting programs exists across the state through ADHS-Parents as Teachers-Healthy Families-those kinds of programs can provide that basic overlay

Not sure if people operating those programs are trained to handle families w/ ASD children

These programs can partner w/ providers to build that capacity.

From a health plan perspective a child-care coordinator should think about providing resources for parenting or home visiting-

Can we make this a recommendation?

We should frame it as leveraging other existing resources across state agencies

Is there a resource list that all health plan case managers can get and know about and be trained about…I just can't imagine all care coordinators knowing these resources

Birth through five- ADHS have a lot of those resources-but were are talking under five. So the question becomes what are the other resources beyond that age group…

AzEIP created a resource page that lists the providers and resources

Can we make a suggestion that AHCCCS work with DES to come up with a list? b/c these services are located w/ DES.

We have to be the connectors-if we have those things we can get those to PCPs and EPSDT coordination- but we need them

Capacity building should happen at all levels and all entry points into the system

if we establish a recommendation for a list of resources for capacity building-I'm shocked that have never done this-

We are going to build consciousness across all ASD providers to think about all things that a family needs to survive.

This mirrors suggestions that have come out of other workgroups in terms of a website that would have links to a lot of different sites.

And it can't just be on the website-b/c poor families sometimes lack the resources and don't have access to the internet.

The key piece this group has to update is the matrix-what we should recommend is that people should be thinking about resources that go beyond ASD treatment-but it wouldn't be this group's responsibility to update those resources.

Any other topic areas in terms of recommendations?

If we put the matrix online-we might run into some confusion- we need a definition page b/c not all PCPs understand the language-and having more information regarding each treatment-guidelines around treatments

I think the states that we looked at have definition pages

Recommend we include the definition page w/ the matrix

Something equivalent going across- some of these terms-parent training for NSP 2

Those systematic studies did not use the same research papers-can't compare those terms-each lit. review defined the terms differently.

We can include all three together-maybe into a category-language-social interaction-cognitive-if any of those terms fit-what outcome showed that is the benefit of that treatment

The reason why the AHRQ studies is so clear is b/c they included the fine details-you would have to look back and find each groupings and look to see what outcomes they look at.

is it meaningful without it? If I am a provider and look at this as a resource even if I have the definition; if I don't know how it actually has improved ASD in some way, would that be helpful to me?

I think one of the plans that we looked is more around that - I'll go back forward it to the group.

So the audience this is directed to is not just behavioral health providers but also PCPs?

Who is determining what treatment will be used after the assessment? So whoever is doing it

I think in some cases it might be the PCP but in other instances it could be another provider

I think after we clarify who the audience will be, we should look at it from the different perspectives of each provider.

Who will be taking the responsibilities?

Find the plan that lays it out better

Leslie-I can compare to what Terry has written down-with respect to getting the child into the correct therapy

Terry-I will put the definitions down

Terry-We have to go back and list studies and see what the outcomes were

Has this workgroup talked about medications?

Very little.

AHRQ has list of meds– specific for ASD- not sure if any other lit. review

Recommendation that AHCCCS might want to take back is as we are looking at AMPM- it says for example PCP can treat ADHD, anxiety and depression. What about ASD? What about kids who have ASD and ADHD? Can this come through from a developmental pediatrician? What about the age? What they are less than 6?

B/c we have changed are formulary for children under 6 for ADHD meds. And we are getting calls from the PCP.

We need to make sure we don't forget dental – pay attention to it

For any child dental is important and overlooked

I think it would be nice- if we can create story boards- if we can incorporate that as part of the dental

Incorporating this- what I hear is that family dentisst are putting children under to do anything- even cleaning. There is risks associated w/ that

They are trying to get patients in and out

Nutrition- registered dietician- feeding therapy- as issues not to neglect-specific feeding issues, nutrition in general-and sleep

Sleep screener-that would be good to know about

You should take her notes there are very comprehensive-we can incorporate the things she lists as part of the check list-

Should we create a check list for feeding?

The communication plan- having something for EPSDT coordinators at the health plans to have for their providers, a manual-maybe they incorporate something about this specific topic- that is what we talked about yesterday-and is not exclusive to that group

Creating check list for children with disability-comorbidity-whatever is created

Is it’s a check list that could be tool for educating PCPs -I do see this as being accepted

It is framing it in another way-looking at kids w/ disability-what are all of the possible things going on — make sure that you take that big picture view on all the potential issues