ASD Advisory Committee Meeting 7-8-15

Evidence-Based Treatment

What are the areas of focus of this group?

Evidence-based practice is a dynamic process of the integration between professional expertise, the individual characteristics of the child and family, and the best available research.

This work group will focus on four areas:

1. Evidence-Based Practice and emerging science
2. Family and member centered care
3. Integrated physical and behavioral healthcare models
4. Establishing a committee that reviews annually evidence based treatment

What do we collectively know about each area of focus?

We have to make sure that our children are screened for comorbidity, I believe in this state we're doing a poor job in doing that…that's not reflective of AHCCCS but, it's our medical system isn't engaged. I think we need to address that as well.

Shouldn't there be genetic or mitochondrial myopathies associated with things like that…

So based on your [remark] saying not say anything bad about AHCCCS or DDD…I want to tell you guys that we don't have a big ego. If you think DDD is doing a bad job about something say so b/c I'm here to make things better…

I have private health insurance too…and I think things are more difficult in this state compared to other states..

I sat on the board of Phoenix Children's Hospital as a family council…and I know that other places such as Boston do a far better job of screening for all the comorbid conditions on a yearly basis…our children should be seen by geneticist on a yearly basis…I don't want us to focus only on the behavioral and forget about the other medical needs

Actually since CRS took over the behavioral health for 95% of its members I can tell you what happens is that the medical piece of it gets ignored and the behavioral health part takes more of a focus…and we were finding that all these kids in behavioral system have been lost…and did not get a follow up…so I totally agree with you.

Also from autism point of view, we don't want a behavior first approach…unless we've ruled out medical cause for that behavior first.

We want an integrated approach to care with both physical and behavioral health

We are here to identify what evidence-based treatment we're going to agree that AHCCCS and its subcontractors are going to fund…we need to add to it who they're going to fund do it…i.e. the qualifications of the people

We need to be careful what we consider as evidence-based because what is considered evidence-based changes rapidly with emerging treatment/ research…also each child is going to be different...so I hope that we don't take a cookie cutter approach

Well let's say evidence based and member and family centered approaches

I think what we need to remember is that evidence-based criteria can change…there are numerous research/ new evidence-based treatments studies conducted every year.. so we need to look at the CDC websites and others to see what's out there.. if I have a child with autism, I would really want to know the up to date information…the cutting edge stuff

We need to decide at what point in time and what criteria these new emerging treatments need to meet…you could find all sort of articles about [emerging treatment] that they did with 2 or 3 people...but it wasn't scientifically formulated or right process were not followed

We need to help families identify what is good emerging treatment…

What I like about EPSDT is that they look at what is working for the child and since autism is based on a behavioral diagnosis it is probably many different autism caused by many different things…so unlike leukemia [that is clear cut] autism is more messy…so we need a little bit more flexible system

re the emerging issue… other therapies have the infrastructure designed around certification/licensing rules…it's important that patient and family members have protections…having been on both sides of that...it's our responsibility to tell people that here is the things that we are very concrete on and there is infrastructure around that…and here may be some things that are up and coming and maybe there is not that infrastructure…but at some point we have to draw the line on what is considered upcoming…what is snake oil…the spirited debate that we're having back and forth is meant to be around that line…I think we all want the best things…but I do get concerned a little bit that if we open the flood gates…what that means for consumers.

We determine the levels of emerging treatment…we need to determine which ones we're going with.

Any research published is going to be 2-3 years old…you're always going to have a lag

The whole point of EPSDT for Medicaid children is that they don't have to wait for 20 years for the new therapy to be approved…so that we don't miss a couple of generations of kids

…I read it and I was disappointed with some of things that were put as emerging…

But you can disagree with it personally, but it's hard to disagree with the science that goes behind this…there is criteria behind this…just like the impact study...there is criteria

I think the difference is that you are reading now that there is a lag…and she is reading emerging as concrete as other people would be reading it

It's important that we don't wait 20 years for this…

I agree with that whole heartedly…you know it doesn't have to be a huge study replicated by 2 different universities…different from the original one…but we need to have some criteria

We don't have a good medical home for our children that is why so many things get missed…

We need to make sure that we have annual reviews

The NSP study has certain guidelines for what is higher quality research...it's got five levels….provides us with a guideline to help families and our system determine what is appropriate

My professional association the ABA has a statement about evidence-based practices, it stresses...it's fairly consistent one across the board that we need to be science-based when we make decisions, but we also have to be family-based…those decisions have to be made with family and the individual child about what they value as an appropriate treatment…not snake oil…but with support of family

Not every child is going to fit in one standard of care so families need to have some choices of what those standards are going to look like

I just want us to be cognizant that we don't lump it all together…I think I'm fine with the emerging research idea but it has to come with the caveat that they are— emerging— for whatever reason…whether they're new, just not enough research….

So what are the key elements that we want to focus on?…we want to use where there is evidence-based guidelines already and we want to include that there are emerging concepts and annual updates to guidelines to keep it current, and to make family-based and person-based, integrated (behavioral and acute)

We are looking for stakeholder input to approve additional evidence-based practices/emerging treatment.

We need people in the specific field of the emerging research to evaluate the research presented to review committee…we to have a multitude of professionals reviewing the research.

Our national committee that does policy for United Healthcare, they have a variety of specialists, developmental specialists, pediatricians, behavioral health, orthopedic surgeons…because you have some of the expertise there…the people that are not experts listen to the input of the people that have more information than them…so I'm assuming the committee of annual reviews has to have some expertise on it

How does the committee get input from stakeholders?

There is literature review and they also get consensus statements from national organizations that are impacted by it…so if it's an EMT type of policy that we are developing than we send it off to the national EMT association and get input

What data do we have?

- Arizona Academy of Pediatrics statement on ASD treatment
- The American Academy of Psychiatry best practice guidelines
- Independent groups that review best practice guidelines:
    - HASE
    - Milliman Care Guidelines
- Commercial healthcare guidelines
- State statutes
- Conduct research on sub-types of Autism—whether there is a differential responses to different treatments
- CMS guidelines
- EPSDT guidelines

What data do we need to obtain?

- Create a shared file (e.g. SharePoint, Google Drive, etc.) for the members of the work group to share documents

Who will obtain the data? Who will do what between now and Aug 12. ?

- All work group members will contribute research to the shared file.