

Evidence-Based Treatment Work Group

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On phone: Nicolette Piano, Terry Mateo, Leslie Paulus, Bryan Davey, Aaron Blocher-Rubin,

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Terry sent out three documents in an email (this morning)

- We should add more recent reports to reference list—NPDC 2014 Study; CMS Impact 2010; and AHRQ Review 2014.
- Bryan distributed a report to some of the members (not sure if all members got copies), the Missouri Autism Guideline Document – the report was very thorough and well done—the report compared all those very complicated reviews.
- We could update so that that we can look at the comparisons across the most recent reviews including CMS recommended one. Terry tried to put it together in a document that he attached (systematic reviews comparisons doc.) and looked at what the Missouri people have done; but also looked at the results of the following studies— CMS/IMPACT, NSP2, NCPD, AHRQ. The review that he put together was for the evidence level 1 and 2 to see what those reviews have shown.
- Terry also included his notes and a concept document on the research from the best practice guidelines.

The areas of focus for the ASD Evidence Based Research workgroup:

- Evidence-based practice and emerging science
- Family and member centered care
- Integrated physical and behavioral health care models
- Establish a community that reviews annually—treatment

Sharon-Does anybody want to add or clarify anything for the focus areas?

I want to throw in what we have been talking about in the previous meeting regarding what is considered evidence based vs. not evidence based

- One of my suggestions is to consider RDI and social cognition therapies—these treatments are being approved in many places—Canada and Australia have approved these therapies across the board for autism
- In California there was a lawsuit and the judge ruled in favor of RDI as appropriate evidence based therapy

Sharon-Is there a consensus that the therapies/ treatments should be considered? [Consensus on this issue around the table]

I have been outspoken about this issue. My only statement is that we don't lump RDI, Floortime, or any of the other emerging therapies with ABA based treatments. When we make our recommendation there needs to be a clear separation between practices that are behavioral health analytic and emerging practices that are not based on ABA.

Are speech therapy services considered one of those required treatments?

There have certainly been discussions in other workgroups about speech therapy and occupational therapy as being part of what needs to be covered depending on the needs of the individual.

I thought we were focusing on the psycho-social behavioral interventions. I don't think they include speech and occupational therapy in these large studies.

They are definitely services that are needed. I don't think that anybody can argue that individuals that need speech therapy—should not get those services. The national standards talked about speech therapy. The general statement across the US is that these treatments are common therapies for ASD.

I agree that RDI and Social Cognition therapy are not ABA based, but I disagree that these treatments are emerging. Those therapies are becoming evidence based.

Sharon-As I attempted to synthesize the highlight of the conversation from June to August among this workgroup, one of the things that I have pulled out is my note at the bottom of page 3-this was a suggestion that a couple of people made—the definition pertains to age 0-5 but could be applied to any age:

- “Evidence based practice means a decision making process which integrates the best available scientifically rigorous research, clinic expertise, individuals characteristics. Evidence based practice is an approach to treatment rather than a specific treatment....”(California Trailer Bill 2009)
- I am interested to know if any of you have thoughts on that definition on evidence based practice?

The language in EPDST doesn't use evidence based, it uses treatment that will ameliorate a child's condition—as long as we can prove that the treatment is going to help that child. The reason why Congress chose that definition was to make sure that we are not cutting children off from a therapy that might prove to be evidence based but there hasn't been enough time for them to collect enough evidence. I think for that reason it's important that we don't exclude treatments such as RDI.

We need to use the yearly review process to evaluate treatments for the different subsets of autism. It is important for families that we continue having this conversation. I like the language in the California Trailer bill for the reason that it allows you to have to say here is what the science says- we have some emerging treatment, but this is what is working for this child and family constellation. Also we also need to add to the notes that AHCCCS and DDD are the agencies funding these treatments.

The national standard report, I would use that as a guideline because it has so much research. Is that in the drop box folder?

It's interesting that you said that EPDST includes emerging but not experimental treatment- I did a quick look in the standards report-it does show Floortime and RDI as emerging treatments.

I was just wondering what kind of professional does these treatments—is it a psychologist?

RDI are usually trained professionals that are always certified- they go through an 18 months training.

Professionals who conduct Floortime—because it is an interdisciplinary treatment—individuals with license in occupational therapy, speech therapy, psychologist, or a special education teacher can get certified to do this intervention.

Currently there is no licensure for that treatment [Floortime]

I think we have some clarity on that - someone may have licensure within a discipline and be using the approaches and techniques to deliver the services for which they are licensed.

EPDST can cover some experimental treatment if you can prove that it will ameliorate your child's condition, and some states have for instance approved hyperbaric chambers for treatment

At some point we have to draw in the sand in the line and say here are the treatments that are evidence based (i.e. therapies that we are confident about and have research that support its validity) and emerging treatment (i.e. therapies that are promising but further studies are needed)

Sharon - For the purposes of this workgroup making recommendations, and remember we are going to be moving towards consensus recommendations to bring to full ASD committee, I am going to suggest that the ultimate decision of where that line is in describing different therapies not be front and center, but rather getting back to the commitment to family and member centered care, integrating behavioral and physical healthcare models, and doing annual reviews—that might be a more productive way to move forward.

[Consensus around the table]

I think what I am hearing is a concern from Cynthia and from others that as we need a definition for evidence based—Trailer bill contains the right language that reflects where the country is for childhood development and evidence based practice for them. What we are recommending is evidence based practices, we are allowing for emerging practices, but here is where we are drawing that line based on what we know today-but that doesn't mean that is not going to change moving forward. I think there is a great need for have behavioral analysis activities-such as social prompting, discrete trial training, etc. There seems to be a schism in the field-where it is this or that-rather than based on that family constellation and that child's reaction to those therapies. So that is why I am more comfortable with EPD definition.

Social thinking is listed as an established treatment in the NCPD.

CMS has also noted that it doesn't have to be one or the other [in terms of ABA vs. non-ABA treatments]—as states develop their plan—there are evidence based practices and emerging practices and not be afraid to include those. I think Missouri did a great job by saying where are not going to show you what to do...but we are going to describe what the best practices are and allow clinicians and families to make the decisions.

My experience in the field is that people take it to be either/or...and I am talking as somebody who was involved in developing the guidelines that have come out of New York...which has been the standard for developing language for autism insurance bills in New York...the problem is that those evidence based treatments were researched in the 1990s and it only covered what was then evidence based treatment at that time and it didn't allow for what is now known as evidence based. What we need to avoid is creating a pigeon hole and say this is the thing. What we need to answer- what is evidence based practice? What is emerging?; How do we make those decision [with regards to classifying a treatment as evidence based or emerging]? how do we ensure that all families regardless of how they enter have access to types of support and services that they need?—because I think that we see a stratification that some families get access to certain things because they are able to articulate what they need and other families not getting same services.

I think you are also going to run into some problems if we don't make some recommendations for what are more clear-cut evidence based versus here is all the evidence, you guys decide. I think knowing how it all works...you'll get discrepancies between health plans, patients, and providers. So there has to be some kind of recommendation on clear-cut evidence based treatments-by what ever kind of definition you decide to use.

I think that is where we are moving a little bit further down the line on the evidence based practices- how do you support practitioners on what evidence based treatments to use; how are they showing that they are implementing it with fidelity? I think that interplay between two of our work group members bear that out, is that it shouldn't be on the parent to do that...but I think we have the practitioners in the field that are not doing that...so how do we assist them making those decisions...so that they could say these are evidence based treatments that we are using...and why I am thinking that this is medically necessary and therefore the health plan should also approve it. Each plan has different practitioners so how do we support those practitioners to think through these decisions.

Because there certain things covered by the state, a lot providers are trained only to make those recommendations. I want families and practitioners to have more things to choose from in terms of therapies that meet the child's needs.

Sharon - Given this conversation, where is the will of the group in terms of making a recommendation on evidence based treatment? Maybe something we could do right now is come up with a definition...

Should we adopt same the definitions for evidence based and emerging treatment used by National Standard guidelines?

Seeking clarification - are you saying not to create a definition and adopt what NSP is saying or the EBP...

It seems to me if there is a highly regarded entity out there doing this work already...and reviewing the information thoroughly, making recommendations, and publishing a national report-there are going to do a much a better job than we are—and I think there intention is to be current and not be behind on research- I think that is the point of a report like that—to me is the best thing—because you are not worried about not including all studies and not being inclusive of all the research .

Who is the body that is reviewing it?

It is published by the National Autism Center-based in Massachusetts—there is a section in the report that explains who they are...what process they are using, etc.

I am concerned that the May institute is such a large provider of ABA services-that is why Missouri approach is better because they look at all of the studies-so that you just don't look at one research summary that could potentially have bias in it.

Sharon - I am not hearing consensus around adopting the National Standards report

I think the methodology that the National Standards employs is definitely above par in terms of what you would see in those systematic reviews. But I also agree with Terry that we have the national standard project but we also have other standards/ reviews that can help us bring forward the best evidence.

What is the availability of parent trainers in this state who are able to deal with the multiple languages of the home?

We do horrible just dealing with therapy.

It's an important is issue to raise...that capacity that needs to be developed in order to help support families and understanding that it is going to be different depending on your culture. If you are going to do parent training than you are going to have to be able to speak to me in my own language.

We can get an interpreter to come...but it would not be the preference

Parent training has been researched—some have classified them as emerging treatments-but it is definitely on the radar-and people are looking at the cost factor—in terms of increasing intensity and decreasing cost. So that is something we should be aware of.

Assignment is to look at Missouri, Minnesota, and New Jersey. And the document that Terry put together for the workgroup