

**Summary of the Proceedings for the
EARLY CHILDHOOD FAMILY SUPPORT COMMUNITY OF PRACTICE (CoP):
INTER-AGENCY MEETING
Washington, DC
(February 28, 2007)**

I. Introduction

This summary is organized around the four goals of the Early Childhood Family Support Community of Practice (CoP) Inter-Agency meeting. The goals of the meeting were:

- A. Expand the Family Support Community of Practice through inter-agency partnerships;
- B. Secure inter-agency consensus on a Family Support Framework;
- C. Brainstorm about the application of evidence-based practice decision-making to the Family Support Framework;
- D. Consider multimedia strategies for advancing the use of evidence-based practice decision-making to support families.

The information provided in this summary is abstracted from the notes taken during the meeting by staff from the Beach Center on Disability.

II. Participants

Researchers, family representatives, and agency officials were present at the meeting. They represented a variety of organizations including:

- Association of University Centers on Disability
- Beach Center on Disability, University of Kansas
- Bloomberg School of Public Health, Johns Hopkins University
- Center for Child Development, Vanderbilt University Medical Center
- Center for Developmental Biology and Perinatal Medicine, National Institute of Child Health and Human Development
- Department of Human Development and Family Studies, Iowa State University
- Department of Special Education, University of Illinois at Urbana-Champaign
- discapacitados abriendose caminos
- Early Intervention Research Institute, Center for Persons with Disabilities, Utah State University
- Family Resource Center Network of Los Angeles County
- Family Voices
- Federation of Families for Children's Mental Health
- FPG Child Development Institute, University of North Carolina at Chapel Hill
- Head Start/Early Head Start
- Maternal and Child Health Bureau
- Mathematica Policy Research, Inc.
- National Institute on Disability and Rehabilitation Research
- National Early Childhood Technical Assistance Center, University of North Carolina
- Office of Special Education and Rehabilitative Services, U.S. Department of Education
- PACER
- Parent to Parent
- Substance Abuse and Mental Health Services Administration
- The Respect ABILITY Law Center
- University of Connecticut Health Center
- U.S. Department of Education
- U.S. Department of Health and Human Services
- Westat

III. Expand the Family Support Community of Practice through inter-agency partnerships

There was consensus throughout the group that expanding the Family Support Community of Practice was a good idea. There were two overriding themes related to this goal: (1) Despite so much positive work in early childhood over the past 30 years many members were discouraged by how little had actually been accomplished with regard to supports to families; and (2) the only way to make significant progress in the coming years is for all of us to work together. The specific issues addressed within this larger discussion are presented below.

A. Researchers

Issues Addressed

- ◆ *Initially, with Part H, early intervention was enmeshed in education. This made it difficult to support families where they were and where they lived. This changed when we inserted “natural environments.” But this devolved into just checking off where you provide service. We need to continue to work on this, preferably through inter-agency partnerships.*
- ◆ *Currently, third party reimbursement is running the system. There is not one state that is fully funded. We don’t have a model to show where it’s working.*
- ◆ *All constituencies within early childhood need to address the acculturation our therapists get. Our therapy schools are still training to be therapists and not early interventionists. So we have a work force that is not trained to do what they are asked to do. As a result most EI professionals think they are providing family support, but they are not.*

Suggestions and Strategies

- ◆ *The State of Maryland has provided a gift to the rest of the country through their online course. It could be a resource that we could all draw on. We could share these Islands of excellence throughout the country.*

B. Family Representatives

Issues Addressed

- ◆ *Maternal and Child Health always seeks solutions with families. Families feel valued in that field.*
- ◆ *SAMHSA values family input but still hasn’t figured out how to get that into the field where the people actually are.*
- ◆ *One fear is that this inter-agency team will just create something that doesn’t really work. Many family members see research being used against families. Providers say “we only have to come out once a week because we are only supposed to train you and not focus on your child” etc.... Families are asking for things, and they’re being ignored. Providers are afraid to write family outcomes on IFSPs, because then they have to provide them.*

- ◆ *Where are the families of the young children in this forum or something similar? Maybe we would get a better answer about what they need / want if they were here.*

Suggestions and Strategies

- ◆ *Trainees need the experience of going around to different communities before they are put in the field.*
- ◆ *Parents as trainers. People are touched by the stories and experiences of other parents. Each constituency present needs to recognize the value of parents' stories to other parents.*

C. Agency Representatives

Issues Addressed

- ◆ *Mandating things will never ever get things done the way they are supposed to be done. We need to develop a "standard of care" like you see in medicine. We have not reached that point in family support where people realize that this is the only way that it will work. We need to find a way to develop a scale where family support is THE standard of care. We have to get the science behind it so there is no question about what is the best way to provide support.*
- ◆ *As a group we need to find a way to address all of the pieces of the problem, pull them together, and create systemic change.*
- ◆ *When we are looking at change, we have to look at the technical parts of it as well as the adaptive (attitudinal) parts. **Basics**: what are people learning? What perspectives are we teaching them to pull in? What experiences are we giving them (trainees)? We have to do all of this, and it is a huge issue but we need to prepare our providers and family leaders so expectations are equal on all sides.*
- ◆ *We are the enemy. We are the ones who created the system that we now want to change. We in DC are probably the worst in the country in terms of figuring out how to work with one another. The only way to make any progress is for all of us to work together.*

Suggestions and Strategies

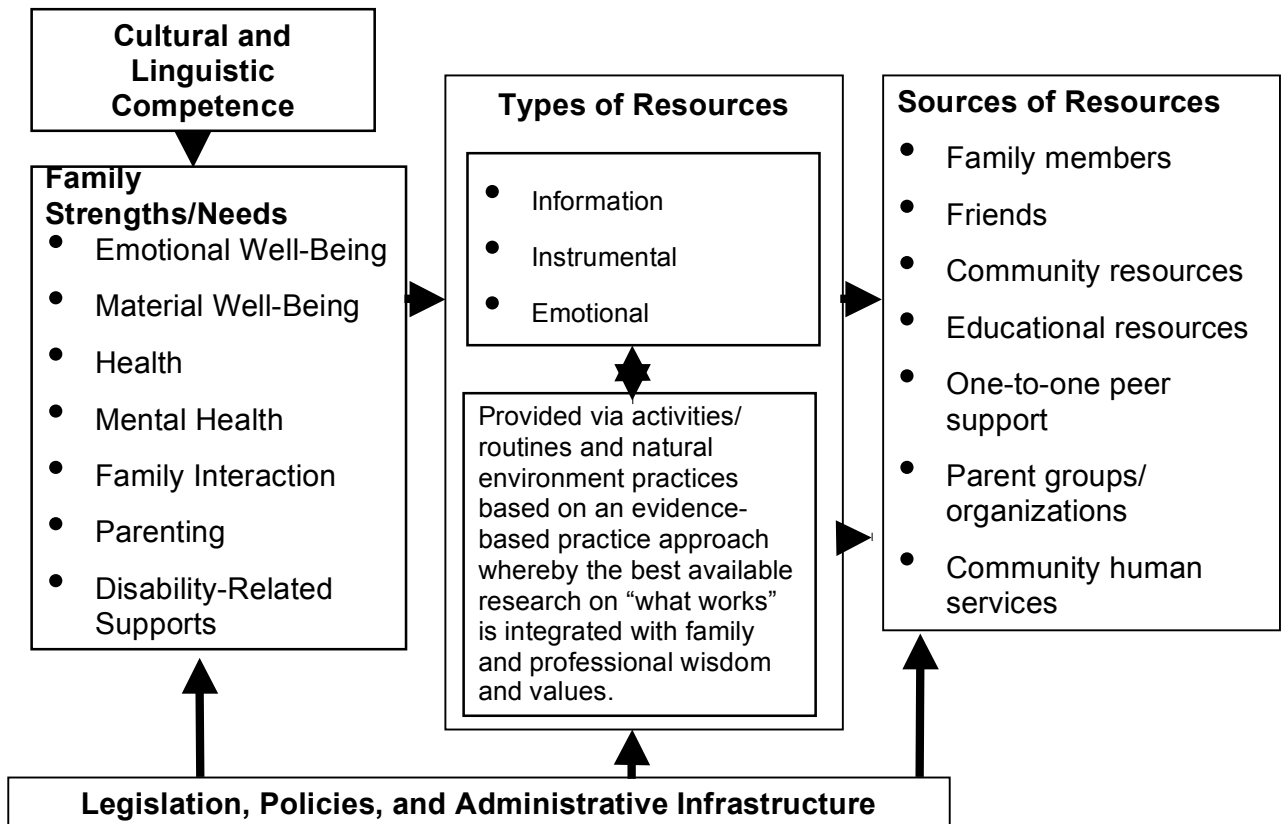
- ◆ *There should be some planning, but there are a lot of other players who are not at this table: private sector, business organizations, other branches of government, and other levels of government. We need to include them.*

IV. Secure inter-agency consensus on a Family Support Framework

In October 2006 several members of the Early Childhood Family Support Community of Practice came together at the DEC conference in Arkansas to create a cumulative understanding of early childhood supports and services. The result of that meeting was the Family Support Framework. The Family Support CoP initially developed the Framework primarily from the point of view of researchers, families, and service

providers related specifically to young children with disabilities and special health care needs. The group at this meeting contained a broad constituency, including children’s mental health and children considered “at risk” for disabilities (i.e., Head Start). One goal of the February 2007 meeting in Washington, DC was to get feedback on the Framework and try to reach consensus within the group about its applicability to this broader group.

Family Support Framework



A. Researchers

Issues Addressed

- ◆ *This is a top-down model. The entry point is a formal system and the power is with the formal system. We need to move out of that formal system and into the real life of families.*
- ◆ *The intent of the framework is to show that any family should have the options in terms of the “source of the resource” and the “type of resource” matched to their need.*

- ◆ *Is this about changing the way of the Part C program operates? A lot of us are used to thinking about legislation and how that will change practice.*
- ◆ *Unless you support families, you are not going to get to the child outcomes. This framework tries to depict the process for providing supports but what we need is definitive research that links family outcomes to child outcomes.*
- ◆ *The framework is not used as an entrance into the system. It is to be used after the family is in EI. As we look at EI, a lot of our frustrations are entry into the system but the framework doesn't deal with that.*

B. Family Representatives

Issues Addressed

- ◆ *Families get ninety percent of the information they need from other families. That does not seem to be represented in the Framework.*
- ◆ *In reality, the problem is that you get very different pieces of information and what we do is assume is that there is this one avenue. We don't have enough clarity about where to go to get information. Families want to get the information, but they don't know where to go.*
- ◆ *We fought hard to have family members be a community resource. A family member should be the first person a new parent contacts; then that relationship is formed, and they are connected. Is this depicted in the Framework?*
- ◆ *Were you planning on having a definition of cultural competence? It is vitally important that whoever is working with a family understand what that family is really saying they need. This is not possible if there is no cultural understanding.*
- ◆ *The best professionals say, "this is my expertise, and this is what I can do. I will point you to other professionals for things I don't know." The best professionals recognize the present situation but also honor the future because the one who is going to be there is the parent and not the EI professional.*

C. Agency Representatives

Issues Addressed

- ◆ *The Framework could break down if the type of resource, the category, does not match the source. You can't match it until you really know specifically what someone is wanting or needing.*
- ◆ *The model may lack in that it doesn't or can't address the tremendous amount of variability in a family's situation. It needs change over time. The evolutionary process tells us that what you are doing now may be different 6 months down the road. We need to respect that diversity of needs and provide multiple entry points for multiple levels of information.*
- ◆ *The Framework seems complex, and it did not seem that families are at the center. SAMSHA is promoting the concept that services are family driven.*
- ◆ *Supports sound like second class citizens. There are real services and then there are supports.*
- ◆ *The science of family support does not have to be real science. I am intrigued with this concept of family wisdom and professional wisdom which is more important*

than training. We invest all this time in training and are still where we were in 1984. How do we create something that is beyond our singular areas of passion? How do we drive this to family driven practice and then we need the data? We need different approaches to data.

- ◆ *The Framework needs to include mental health. It is also important to have a category like “medical home.”*
- ◆ *The conceptual framework is intriguing, but it’s not going to help a real family. One of the problems is that research begets research begets research. We need to balance the conceptual work with the need to do something.*

Suggestions and Strategies

- ◆ *Congress is considering funding a national children’s study tracking 100,000 infants over the next 21 years. Part of that authorization was to have OMB and NICHD. There was not anything related to the support families receive or get or want. A percentage of those families will have children with disabilities. Maybe we want to ask a family support question that could be considered for a protocol. We don’t have a data set like that – 100,000. The proposed funding is 69 million first year, 111 million the last year. They are going after the first 3rd of the study sites in the first year. Before they move forward, the protocol will go through review. Assuming that it happens, each year will have a representative sample of children and families. One concern is the “power” of a question. Could you ask a question that affected every family that has a child with a disability? What would that question would be? What is the infrastructure for doing research on these kinds of questions? It would be a very challenging thing to develop but without it we will not go anywhere.*

V. **Application of evidence-based practice decision-making to the Family Support Framework**

Evidence-based practice (EBP) is “A decision-making process that integrates the best available research evidence with family and professional wisdom and values” (Buysse & Wesley 2006). Patricia Snyder, Virginia Buysse, and Pam Winton lead the discussion on EBP decision-making. Their initial presentation included a definition of EBP and a discussion of the components: Research evidence, professional wisdom, professional values, family wisdom, and family values.

A. **Researchers**

Issues Addressed

- ◆ *Wisdom at the individual level could be aggregated across families representing different cultural and linguistic groups. Across agencies and across issues, there is wisdom that can be shared that is not in the professional literature. We need the voices of those families.*
- ◆ *There are great products, family and professional, that are sitting on shelves. How do we harness these products?*
- ◆ *I think it is challenging to think about collecting all of this, if we think about wisdom around selected practices. Maybe we can think about wisdom within the Framework or DEC Recommended Practices. Let’s start small and with one practice we are all familiar with. We can see what happens through qualitative analysis—a systematic, rigorously analyzed collection of family wisdom. Maybe it produces a set of stories. EBP is a process. Once this is done, then there might be other wisdom collected around “what do you do in a difficult situation.” We can’t ever collect all the wisdom and values.*
- ◆ *Values: A 50-year old Britannica encyclopedia said values were about color, hues. Wikipedia and other places described values as ideologies, beliefs, interests. So that is just a way to begin the discussion of values.*
- ◆ *I would like to know how to get research on values. One question is related to the role of values among early childhood professionals. There is research that shows that doctors’ values sometimes influence the advice they give to patients particularly around issues of abortion and birth control. Is it the same for early childhood professionals? We have to put these issues out there. What happens when values clash? Decision making is a social constructed activity. Values play a very important role in this process.*
- ◆ *Do we have collective values in our field? Do we start with our codes of ethics (DEC, NAEYC, CEC, Parents as Teachers)? Which ones do we value? Do we try to put them on the table and find the commonalities? Or do we find a “third space” that is not my opinion or your opinion but where we can agree and have a dialogue. We need to do some work in our field on this discussion of values.*
- ◆ *The issue of values has implications for our work. We need to take the boxes we showed, deconstruct them and try to understand them in a systematic way. It has to have rigor or it will do us no good in this era of accountability.*
- ◆ *We need to think carefully about using “values,” because it has so many positive and negative connotations that go with it. It has more of a negative connotation in*

this conversation. Someone could use “values” to do something that is hurtful. At the same time, maybe we have to grab hold of it because people use values to make decisions.

- ◆ *It is important that we not get too esoteric and always bring the idea of EBP and its components back to a specific practice to keep it real. The key to EBP is that it is a decision-making process.*

Suggestions and Strategies

- ◆ *In order to make research evidence available to next generation families and professionals, we can put it online and make it downloadable so they can listen to it on their iPod.*

B. Family Representatives

Issues Addressed

- ◆ *For parents of children with disabilities, it is validating for family wisdom and family values to be integral to EBP. It can refer to both individual and collective wisdom. The question is how do we collect and codify family wisdom?*
- ◆ *Families have written a lot for one another (i.e., tip sheets). They have written diaries. There are listserves full of family wisdom.*
- ◆ *In terms of when something is Family wisdom and when it is not: Every shoe does not have to fit every foot. When a shoe doesn't fit a certain person, that does not mean it isn't a shoe. The same is true of Family wisdom.*
- ◆ *No knowledge is permanent. All knowledge changes over time. If we think about the evidence base of medicine, people's genes inside their bodies make a difference in how that drug works. All research is flawed because it is only based on how we do it at the time we knew it. Both the research side of evidence and the “wisdom” side of evidence is flawed as well.*
- ◆ *Family organizations have all the information on Family wisdom and values that we could ever want. Family and family health resource centers all around the country have information about strategies. We need to figure out how this can inform EBP but more importantly how we can get that resource out to families and how do we help them?*
- ◆ *It is true that there is a lot of information out there, but it is important to remember that often every day is a struggle for a family; and you can give them 10 things, but if the one thing they need on that day is not included then the information is useless. It is important that we listen to families actual needs if we want to help them.*

C. Agency Representatives

Issues Addressed

- ◆ *Next generation parents access information in a whole different way. There are listserves on all kinds of information—just in time information. Autism Speaks has an open discussion on ABA. That is more informative than 12 research articles. We could really develop a wiki site where you have a self-correcting information. With enough people’s comments, somehow the truth emerges from it. Including that from the experiences.*
- ◆ *Some agencies have an interest in looking at many different ways to identify family wisdom. MCHB would be interested in being a player. This provides a whole new dimension of services.*
- ◆ *Several words are being used as if they are equivalent, but they are not. Wisdom, opinion, bias. Don’t talk about expert wisdom. Talk about expert opinion. It is sometimes necessary that you use opinion, and it is nice to have an expert. Concerned about use of word “wisdom” which most people associate with “good.” Families could change their opinion about what is good at the appropriate time. Question: What is right? Both, neither, but situational?*
- ◆ *One concern about using the term evidence-based practice is that it already exists in the minds of people. Part of what you will stumble over is, “no, no, that is not what we mean by that.” That will get in the way of trying to communicate this exciting process. Perhaps we could call it “value-based practices.” A practice based in the best science available, what actually works for families, and what works for practitioners. Let’s not get stuck on that old term.*
- ◆ *Any time we talk about values or have a definition, it is good to integrate cultural and linguistic competence into your thinking. Otherwise you will end up having to add things.*

Suggestions and Strategies

- ◆ *Conduct a study in which you do a factor analysis of 11,000 comments from families. Until we do that we don’t have a form of wisdom that is justifiable to funding agencies and policy makers.*
- ◆ *We know that often practitioners are not doing what we developed and we get frustrated. Maybe it is because we did not involve them in the process. They should be involved in the development of evidence-based practice.*

VI. Consider multimedia strategies for advancing the use of evidence-based practice decision-making to support families:

A. Researchers

Issues Addressed

- ◆ *What would it take to pull together the best available research on professional and family wisdom? Who would do the work to organize all of this information?*
- ◆ *We have a national center called Champions for Inclusive Communities that might be able to do some of it.*

B. Family Representatives

Issues Addressed

- ◆ *The whole notion of community activities, this is an informal resource and you talk to the family down the block. The family-to-family connection happens in this informal way and not through a tip sheet or the internet. The other thing is the educational methodologies. We have to be careful that we don't set families up. For example you may provide a bunch of information to a parent, take that to the school, and the school will say, "don't tell us how to do our jobs."*

Suggestions and Strategies

- ◆ *Using the internet to provide information to families is fine, but you need to remember that a lot of families in poverty do not have access to the internet. If you go to the library nobody is going to teach you how to use the computer. Perhaps things could be made available on DVDs. There are relatively inexpensive DVD players, and this might be a good alternative.*

C. Agency Representatives

Issues Addressed

- ◆ *There is something developed at The University of Iowa. It's called the Global Campus. They use a software program called Illuminate. It provides online web conferencing capabilities.*
- ◆ *There is another thing called "e-granary" that holds one terabyte of information. It has potential that you wouldn't believe. You could put all of the Department of Education's information on it, and it's cheap. One of the strengths of it is that you don't have to have internet access. You can burn everything onto a cd. Basically, you can pick what you have on them. You can say we want early intervention information. It looks and feels like the internet.*

Suggestions and Strategies

- ◆ *Really developing a wiki site where you have a self-correcting information. With enough people's comments, somehow the truth emerges from it. Including that from the experiences.*

VI. General Themes from the inter-agency meeting

- ◆ *Despite positive work in early childhood over the past 30 years, many of us are discouraged by how little has been accomplished with regard to family supports.*
- ◆ *The only way to make progress in the area of family supports is for all constituencies represented at the meeting to work together. Some felt we needed to involve more constituencies; others felt we were just the right size. As a whole the group expressed support and enthusiasm for continuing to work together.*
- ◆ *We need to continue to work on the Family Support Framework.*
- ◆ *We need to continue the discussion of evidence-based practice decision-making with particular emphasis on family and professional wisdom and values.*

Suggestions and Strategies

- ◆ *We continue to work together as a Community of Practice using online technologies. The Beach Center recently received a grant that enables them to develop an online site for our CoP. The site should be up and fully functional by May 1, 2007.*

VII. Next Steps

The group agreed to look into planning a conference to be held next year at this time. We discussed two options. The first was to “take one slice” of the EBP decision-making process and focus the conference on the family wisdom aspects of a couple of elements of the Family Support Framework. The conference might be a “national launch” of what family wisdom is, how it can be useful to families and practitioners in EBP decision-making, and how to make it available through web-based, multi-media formats. A second option was to have a conference to pull together the best available research, again in light of the Family Supports Framework and for sharing through technology. A total of 13 people signed up to serve on the planning committee. There are several possibilities for funding to support such a conference and associated work (i.e., synthesizing literature, compiling family wisdom), which we will explore.

Suggestions and Strategies from the whole group

- ◆ *Have family leaders host a conference and invite researchers to come and share their research with us.*
- ◆ *Jim Hanson suggested that some of NICHD's proposal opportunities for conferences could be a source of funding.*

- ◆ *Tiina Urv suggested involving young researchers who may be more open to partnership models.*
- ◆ *Also have family leaders present their needs and ideas to researchers and funding agencies.*
- ◆ *Make sure that the conference is family friendly. For example, would there be a cost for families or some way to subsidize their trip?*
- ◆ *It would also be a good time to bring in junior researchers. If we get younger people in right now to listen to the parents, it may change the way they approach their research.*
- ◆ *It would also be important that we invite early childhood practitioners who can listen to both the family and researcher presentations.*
- ◆ *At NIH there is an active effort to include the voices of consumers in decisions about priorities and the qualities of research proposals. There is a group called friends of NICHD, and we consult them regularly when coming up with RFPs. In terms of convening a meeting, we offer grants that require the inclusion of young investigators and minorities.*
- ◆ *Conferences occur to share information, but we are still trying to develop something. Is this conference a way to continue the development of the Frameworks we discussed? We need more concentrated discussion on each of them. Also more concentrated discussion around wisdom and values. Finally, at one point we were talking about outcomes. We should identify those and then run those through EBP with a small work group like this.*
- ◆ *We have been trying to invest strategically. In the early years we invested in dissemination and learned that this makes very little change. We've learned that behavior change usually takes a lot of hands-on support at the community level. So this brings in a hierarchy of our attempting to help states build infrastructure to support communities. The work supporting PBS has been successful, and we're trying to support other programs to work in the same way.*
- ◆ *The Maternal and Child Health Bureau has a small research program but it is very small. It might be a resource for the research end of this. We are service oriented. If we have practices we can run with then we will. On the implementation side, we can be tremendous help. We are supportive of the research and will support it as much as we can. We are very supportive of this whole process.*