What is Effective Early Intervention with Families of Infant and Toddlers with Disabilities?

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Good morning! I am glad to be here, back amongst people I worked with for nearly 5 years in the 1990s. I want to thank them for making the signs so prominent so we could all know where to go! It is nice to be with others who share the idea that looking at the world from another's perspective is important. I hope to be able to do justice to this topic – "What is Effective Early Intervention with Families of Infants and Toddlers with Disabilities?" Some caveats - I think it is a highly subjective question; we could look at it from so many angles and find a myriad of answers, all of them complex. I think we also need to say right from the start that effective practice with one family could look very different than effective practice with another family. So with that in mind, I want to just outline a few of the lens through which we could look at what "EFFECTIVE" might mean. It can't be a set of Do This, Don't Do That rules – the very notion of effective seems to suggest that it is tailored to a family's needs, so to try to define it makes it risky that it becomes formulaic, prescriptive or coming from a set of "SHOULDS" that can get any of us defensive and at points in time actually impair the ability to implement best practices.

From a broad based perspective, noted author on highly effective people, Steven Covey, would suggest that effectiveness includes beginning with the end in mind, and seeking first to understand, then to be understood. With a bit of a stretch and some creative thinking, those could be concepts we apply to early intervention. I will expand on this idea in a bit.

The federal legislation would suggest that effective practice involves forming partnerships with families, doing "multidisciplinary evaluations, or "teaming," writing specific goals and objectives in the Individualized Family Service Plan, the "IFSP" and providing learning opportunities in natural environments, and of course documenting and measuring everything along the way, all the while operating on a budget that has been declining since 2004.

Research tells us many things. From the field of infant mental health, one interesting study noted that giving concrete support to economically vulnerable parents of infants increased the mothers' warmth and responsivity to their infant, so the notion of meeting concrete needs might be hugely important in the world of early intervention. We know that Dunst, Trivette, Bruder, Dempsey and others have tried to quantify the exact type of help-giving behavior that leads to parents' feelings of empowerment, with the underlying assumption that empowerment would lead to increased feelings of competency, control and confidence.

Zero to Three, the noted think tank of early childhood and the National Center for Infants, Toddlers and Families reminds us that "no two families cope with the diagnosis of a child's developmental disability in exactly the same way," and suggests that effective early intervention resides in respecting those differences, learning about and building upon family strengths, and developing "meaningful and caring partnerships with parents."

Parents of children with special needs say that the collaborative process with professionals helps develop their feelings of competency and confidence at a time when they might otherwise be swimming in a seemingly endless sea of worry, guilt, loneliness and anger. The parent-to-parent relationships often help lend hope, companionship, and understanding in an otherwise frightening situation. Writers such as our own Janice Fialka have helped convey the message that parents say that the careful attention of an attuned interventionist also "holds" worries and fears, helping make managing the emotions related to a new diagnosis less overwhelming, at least for a moment.

In the world of Infant Mental Health, my world/my professional identification, we often ask ourselves, "What about the Baby? What would this baby want us to do? If she could talk, what would she say? What do his cries or coos tell us? What does her hiccup and flushed face let us know?" And thus, that is where I begin….what would the baby have us know?

What would a baby say about beginning with the end in mind? It might be that she would wish to grow up, to whatever age that might be, surrounded by family members,… whoever is defined as family in her community, … that feel secure in their ability to know and understand her. We know that parents who have their own history of secure relationships are more likely to accurately perceive and sensitively respond to their baby's cues. In this respect, we would be wise to call upon the advice of a well known pediatrician and analyst, Dr. Donald Winnicott, who admonished the medical community in the mid 1900s to do or say nothing in an infant's first year of life to make a parent feel uncertain or criticized. What a tall order to be so careful and thoughtful about if, how, when and why we say what we say and do what we do. We often forget the power we hold with the families we serve, especially in the first year, or until they gain their footing. Winnicott knew that the "ordinary devoted mother" didn't need any more advice – she just needed to be encouraged to listen to her own wisdom….then she would come to know the baby in profound ways. This knowing that he suggested has been validated by research that found that when parents and professionals have a differing perspective or disagreement on a child's current development, the parent is right 75% of the time.

So this brings me to my first recommendation for Best Practice. We already know that parent and professional relationships matter to outcomes. But we don't always know what is required to create a relationship or foster a truly deep one. We have years of material now alluding to its necessity, but have we truly broken down what it means? I would suggest, and this thought arises out of infancy studies and out of the field of

Infant Mental Health, that empathic awareness and careful attention to the parent(s) and their experience is a cornerstone to partnership. We know from the work of Allan Schore that when someone feels deeply understood and attended to, their right prefrontal cortex, the seat of logic and reasoning, is firing…creating neuronal activity in the problem solving area of the brain. Why is that so important? Think of the last time you were with a really good friend or someone with an intuitive way of listening and you discussed a difficult problem…sometimes the sheer act of being listened to creates a solution. Now, I'm not suggesting that such an approach would necessarily increase a parent's understanding of how to implement a particular exercise, but it might be just enough to help him or her feel settled enough to even begin to think about how to fit another task into the day, or give them enough extra oomph to "resist" us and say, "No, I think there is another way"…and be right. But why else is this attunement so important? When a baby feels known, understood, "held in the mind of another" – it creates a sense of integrity, of a sense of identity –even from a young age. So beginning with the end in mind also holds with it the notion that this child can and will develop an identity, be a fully functioning – to the best of his ability – member of society…that he has something to contribute just as his siblings, cousins and the neighborhood kids. Being held in the mind of another, deeply understood…if we can avoid the jargon, brusqueness, and sometimes intrusiveness of "intervention" and still provide some of our collaborative expertise in knowing the areas of a child that are our specialties – maybe we can contribute in some way to a baby feeling known and understood. And I think that connects with Covey's idea that relationships are enhanced when we seek first to understand.

What else might the baby say? He might let us know that his mom or dad really does know him best, and that despite his difficulties in conveying his wishes, he feels best when it is mom or dad that is with him during hard tasks such as physical therapy. When we see a baby or toddler, sobbing as they head into a therapy room without their parent (and that still happens) we have to wonder - what did it cost that mother or father emotionally to go along with a plan that said an OT would better be able to work with the child if the parent wasn't in the room? And if that were the case, what might it say about how that mother or father feels, being told that her child is better off without them during sessions?

A baby might also let us know that she would greatly appreciate it if we helped her parents with their feelings, so they could be as emotionally available as possible to her. That doesn't mean forcing "grief work" or breaking through "denial" or making her do kangaroo care with her child just because it is good for the preemie. It may mean acknowledging that holding a baby so fragile and wondering if she is going to die is just too hard sometimes. It may mean putting down the chart and really listening to how resentful a parent feels this week. Conversely in may mean really allowing oneself to feel joy with the family when an important milestone is reached. This might be a good spot for "Seek first to Understand" to be illuminated. It could go something like this…. A physical therapist is working with a family and it becomes increasingly clear that a

child is going to need adaptive equipment. Despite all best efforts, in spite of all the logical and rational reasons and wisdom the team discusses, the parents resist getting equipment. Concurrently, and perhaps not coincidentally to the "resistance", the family's nine month old is beginning to crawl. Is there perhaps a connection between the resistance and the emotional, not just physical adaptations, which need to be made as well? Could they be grappling with the realization that their 2 year old is now behind their nine month old in heartbreakingly obvious ways? Maybe they have been so focused on working toward crawling that everyone missed the emotional adaptations the family needs to make to be able to accept equipment. In an instance like this, an interventionist would say that equipment is going to be absolutely necessary to promoting mobility for this child but also, and equally as clearly, the family may or may not choose to follow through with recommendations. A less effective interventionist might be heard to say "Can you believe that family, can you believe they won't…can you believe…?" How are we to address this normative reaction of an interventionist feeling thwarted by a family? It is here that I would like to talk about a Best Practice that is discussed in mental health work but is increasingly being described in the field of early intervention, and that is the notion of "Reflective Practice." Simply put, but not so simply implemented, it is the notion that when we work with vulnerable families, we will have feelings about what we do, what we see, what we hear. The sense that we should be able to manage the emotions on our own is nearly ludicrous when you think about it. So one aspect of Reflective Practice is to have a place to think about and reflect upon what it feels like to emotionally open up and take in a baby and family, a place where we feel refueled so we can be there for families in a deep and meaningful way. The second aspect of Reflective Practice helps us give more meat to the bones of Family Centered Practice. Most of us get trained in the tools of our craft – the games to play that increases language, the exercises that address spasticity, the toy to bring on a home visit to spark curiosity. None of that addresses the *how* of what we do. Do we come with an agenda and a sense that we are in control? Do we approach with the belief that we are the expert and need to impart our knowledge? Or do we approach with humility and humbleness, as Michael Trout notes, to sit at the feet of a family and learn from them? In today's fast paced world, the hows of what we do are often overridden by the billing of what we do, or the documentation of what we do. But there is another way, and a way I believe cuts across disciplines…and that is to leave some time and space to talk about the *how* of what we do. In an organization that understands the need for reflective practice, a supervisor might be able to say to that physical therapist "It is really hard, when you know how much this equipment might help this child, to understand why a family might choose not to pursue it. I wonder what that is like for you?" That process of holding the practitioner's anger and resentment might in some respects be the very skill set that needs to be developed so that the practitioner is able to go beyond the rote attending – "Yes, it is really hard to get equipment because it means you have to admit your child's not going to be walking" (i.e. let's get on with it). Within a place of reflective supervision, a therapist might learn come to understand instead that these nodal moments in communication offer the opportunity to say, within a *relationship* with a family, "My guess is that it could be

emotionally hard to get this equipment…would it be helpful to talk about it?" One need not be a licensed mental health professional to listen. So a second, and I think under-addressed best practice in early intervention, is building and sustaining teams of people who are willing to emotionally be there with families and giving them the space and time to do so. Some families will welcome us in this capacity, some families won't, but if we truly understand the power of relationships – interventionist to parent, parent to children, and vice versa- then teaching about it, helping professionals reflect on building relationships and supporting their emotional availability to sustain them, needs to be incorporated in an early intervention agenda. As Dan Stern, noted infant psychiatrist, offered at the 2006 World Congress for Infant Mental Health, "We have been dragged, kicking and screaming, to the realization that it is the relationship that does the work."

So how do we teach this in our programs? One strategy is the notion of Parallel Process – Do Unto Others as You Would Have Others Do Unto Others (Jeree Pawl). If I want a student to be humble and curious, I may have to be humble and curious with her. If we can hold in our heads that the process of learning is partly experiential, then we can begin to think about what our students experience with us; we can try to illuminate how the families they will serve may experience them. We can incorporate some basic principles of infant mental health into our content; we can advocate for reflective practice and encourage students to value listening as much as talking, along with some strategies for asking questions. We might guest lecture for each other – you can come talk to my child development class about language development and I'll come talk to your class about attachment and social emotional development. The concept of teaming can begin in the classroom. If we approach thoughtfully the notion that effectiveness is expanded by beginning with the end in mind, we are that much closer to sending our students off with skills that embody at least some aspects of best practice. If they leave knowing that relationships matter – to them, to the parents, to the siblings and most of all to the babies, I think we will have accomplished something important. And I think the babies would agree.