

New Assessment: Early Childhood Resources

Online Documents

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The Phylosophy Behind Assessment: What is it that we really want?

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Like it is with many families, our dreams about children and family grew as my pregnancy progressed. So many of those dreams lay at a more or less subconscious level, which only in retrospect appear so clear. Having a child and becoming a family defined not only ourselves as parents, but became a way of acting out and demonstrating to those around us what our values and beliefs were. Our preparation for childbirth began before pregnancy as we carefully created an atmosphere of peace between ourselves and actively changed lifestyles to include regular exercise and good food. We would have a home birth, non-sterile and filled with personal ritual. Scott would catch the baby and cut the cord. I would labor without pain-killers (I hoped!). We would be surrounded by our closest family and friends whose presence would forever cement the bond we all would make with the child.

We would be the kind of family who played together, especially out-of-doors. We would be the kind of family that displayed respect for each other and listened to each other's stories. We would be the kind of family that camped together, lived together in our wood-heated, passive solar home in the mountains — demonstrating a non-materialistic life. Our children would breastfeed and eat healthy foods and would consider the woods behind our home their toy box.

That did not happen. I rapidly developed a life-threatening illness, necessitating the emergency delivery of Evan just several hours shy of what would have been my own death. Strangers surrounded us; strangers told us our baby would certainly die. The delivery took place in an operating room and Scott peered in through a small window as I lay unconscious. We were the last to touch our boy and his first sensations were the intrusive and painful sticks of needles and tubes. We could not hold him, his

immature gut could not hold my milk, we did not get to show him off to our family and friends. He did not come home for a year, and when he did, our home in the mountains induced further life-threatening complications.

Massive life support kept our son alive, kept him with us, but it also separated us —creating fear and distance. This technology was a necessary intervention if he were to stay alive; but it came at a cost. It profoundly threatened the bond we needed to make with our infant. How could we feel competent as parents, feel needed, if we had to obtain permission before we even touched our son? How could we feel like a family with two of us so sick we could barely interact? How could Evan come to feel the world was a safe place when pain was the dominant input? How could Evan know his mother and father when we could not hold him, could not feed him or care for his basic needs?

ASSESSMENT PARADIGM # 1: TYPICAL IS OPTIMAL

Why assess when a child does not develop the way her peers do? What are the goals behind assessment and intervention? To help the child ‘catch up’ to his peers? To get the child to behave, interact and move about like other children? And if the child can never catch up, what then? To get as close as possible? These questions, and their answers dive to the roots of this culture’s beliefs and values about what constitutes quality of life. If the goal of intervention is to ‘get as close as possible,’ are we as a culture saying through implication that typical (what is most often seen) is best? Are we implying that children with lifelong delays are not able to enjoy life, feel good about themselves or belong in a meaningful way to their family and culture around them as much as other children, and that, therefore, the proper task of assessment and intervention is to get them ‘as close as possible’?

ASSESSMENT PARADIGM # 2: QUALITY OF LIFE BELONGS TO EVERYONE

Perhaps we as a culture are saying that chronic and serious illness and developmental delays/disabilities present the individual with barriers to quality of life, membership and a personal sense of competence, and that the proper focus of intervention is to help find ways around those barriers. The difference between the two paradigms appears minimal, but the distinction is there. The implication, or attitude behind the second paradigm, is that having a disability or living with a serious or chronic health problem is one of the many, many manifestations of being human and alive, but that in this culture, in

this time, attitudes and institutions are such that having a disability presents a person with some hard to overcome obstacles. Conversely, one of the implications or attitudes behind the first paradigm is that, since having a disability or health problem is always an obvious ‘negative,’ we must look for ways to circumvent the disability. Paradigm # 1 implies that being other than typical is not desirable or valuable, whereas the second implies that having a disability is neither good nor bad, and focuses instead on how a culture views this person and whether or not this person can access life in the same ways.

GETTING PERSONAL: WHAT ARE YOUR VIEWS?

It is very important for people working with families and young children to think about this issue, because this can often be the central issue a family faces when they hear about their child’s diagnosis. Though often occurring on a subconscious level, families are wrestling with deep-rooted beliefs about being human and being a family. Is a disability a ‘defect?’ Is a disability a difference that should be valued? They love their child, but are they loving a defect? What are they to think when they receive sympathy cards instead of congratulations cards? What will people think of them and their child? Does the disability mean their child can never be fully or really human? Would we, if we could, eliminate all disabilities or health issues from the human race, or is that an integral part of the human experience? An individual’s **culture** determines some of the answers to these questions. Some cultures may value the disability itself, believing that it is a kind of gift. Others may believe that the disability is a sign that the parents did something wrong; others still might have conflicting beliefs. Any person working with families must have examined their own feelings about disabilities and chronic illness, and must continue to do so on some level with each new family they meet.

Whichever paradigm (or mixture of the two) that you feel most strongly about, in the end it is the family who will be living with its values and decisions, and it is the family who will define the context in which assessment and intervention occur. It is up to you to know your beliefs not so that you can tell that to the family, but so that you do not mix your beliefs up with theirs.

The family (and, most obviously, the child who belongs to it) will have to live with whatever decisions are made regarding the care of their child. When considering any type of intervention, the question must be asked “How will this intervention support or compromise the family (the ‘real’ center of the *Framework*)?” The starting point is the family. While they will doubtless need assistance, only they can indicate how something will impact their quality of life, and only they can define what quality of life

means — to them.

The PC Framework's Core

At the center of the *PC Framework* lies the individual in her or his total environment. Three areas comprise this total environment that surrounds any given individual or child: *Quality of Life*, *Membership* and *Personal Sense of Competence*. How each of the three is defined is left open for interpretation, depending on the context of each situation; still, each area requires some description:

Quality of Life looks at things like sense of well being, safety, happiness, emotional security, health, and basic living conditions as defined by each individual.

Membership looks at the ways in which the individual is able to interact and feel a part of her or his family, kin and community.

Personal Sense of Competence looks at how the individual feels about her or his actions in the world: Is the individual satisfied with their accomplishments on their own terms? Can they communicate and/or effect influence on their environment (people and circumstances) in some way? Does the child and family feel a sense of worth or purpose?

It is clear that these areas interlock and that there is no absolute distinction among the three of them. The definitions themselves are highly contextual. It is up to the individual and the family to decide for themselves what each area means.

A brief 'pause' is warranted here to talk about the physical and verbal layout of the *PC Framework*. Although it shouldn't be, it is probably easy to forget that tied to the *Individual* in the center is a family. *This is especially true for young children*. You can not consider an individual child apart from her *Membership* in a family; the *Quality of Life* for a specific child is closely linked (and vice versa) to the quality of life for the family as a whole. This same idea applies also to *Personal Sense of Competence*. The younger the child, the more the parents are responsible for defining and shaping the child's values, preferences, and beliefs. While the infant has certainly arrived in this world with their own unique temperament and set of *Givens*, it is their parents who are making all the decisions for them. When

deciding whether or not to remove life support from an infant who has had multiple complications during birth is a dramatic example, but nonetheless it *is* the family who must consider the *Quality of Life* of their infant and their own family unit.

In this context, any person working with a family must remember the following things about any assessment or intervention:

- ***The act of observing and assessing changes things.*** It is nearly, if not totally, impossible for changes NOT to occur as a result of a third party observation and assessment. How a family reacts to this change will depend on a myriad of factors, not the least important being how sensitive the observer is to the inherent difficulty in any kind of change.

- ***Interventions always have both positive and negative impacts on the family and child.*** It is also nearly impossible to choose to implement an intervention which does NOT (even if it is temporary) have some negative impact on *Quality of Life, Membership* and *Personal Sense of Competence*. Consider finding the intervention that appears to have the least negative, and the most positive, impact. Check frequently with the family to determine that the impact remains on the positive side. Recognize that change to any given family system will be difficult.

- ***Children and their families are one unit, (except in cases of clear and present danger).*** It is again almost always impossible to separate the child from his family when considering issues at the center of the *Framework*. If you don't have the family in mind when making recommendations or suggesting treatments, then you have left out a considerable portion of that child's *Membership, Quality of Life, and Personal Sense of Competence*.

At the hub of the framework is the child and the status of their *Membership* within their family. The child and their family are the quality assurance piece here. They are the deciding factor in how suggested interventions will or will not affect their family. Only they can judge if *Quality of Life* issues, *Membership* issues or their *Personal (family) Sense of Competence* is threatened or satisfied by suggested interventions. It is important to back up, however, and remember that every other area of the *PC Framework* impacts that center. That intervention is, in part, the attempt to mitigate whatever impacts are found to be negative *or*, enhance any effects found to be positive. The most important question remains unchanged; *what supports and what compromises this child's Quality of Life, Membership, and Personal*

Sense of Competence?

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