

Infant Observation of Special Needs Babies

by Lic. Gabriel Federico

*"Babies do not remember
having received adequate support:
They remember the traumatic experience
of not having received it."
Donald Winnicott*

The special need of a newborn child is like the falling of a bomb when you were least expecting it, and which when it detonates makes an impact mainly on the bond that is being built between mother and child. This bond does not simply appear at the baby's birth; the bond is being formed during pregnancy or even earlier and is consolidated after birth. But in this case, when the baby or the circumstances of its birth are different, there is no time to build the bond; the biological process is cut short by the situation, changing the link status and affecting what was being built. At the beginning of the new reality, many fragments of this relationship will disappear forever, others become deeply hidden and some pieces will take a lot of time to adjust, heal and repair the cracks in the process. This will depend on the personal strengths which the mother can count on in order to cope with the new situation in which she finds herself, and the support of those professionals who provide an appropriate and respectful treatment of the situation; those whom fate brings together. The reality will be adjusted to the particular characteristics of the actual baby, different from the fantasy, and that will develop with particular and unique needs.

A premature baby or a child with disabilities is not within the plans of most people. A different baby is not what families expect, on the contrary, illusions and expectations are always much higher than the reality.

Worries about deformities or mal-formations, may have crossed the mother's mind during the pregnancy, but they disappear when the pregnancy is strengthened and obstetric controls are increased, and these thoughts never get to play a leading role. Therefore a baby born different is a baby who has particular characteristics that were not expected, which were not desired, about which nothing is known, and even those of which the parents don't want to know.

Alongside, we have the person who presents the diagnosis, who usually doesn't know best, but who is encouraging. And of course this generates in parents a state of shock, anxiety, distrust, anger, disgust, sadness and in some cases, a sense of self sufficiency, where the parents are confident in their ability to take over and reorganize the situation.

When we talk about disability we include everything that moves away from what is expected, and which deviates from normal patterns of growth, behavior or development. We refer both to what is seen and what cannot be distinguished without specialized study. We're talking about, among other things, medical conditions such as hydrocephalus, lack of limbs, cleft lip or cleft palate, shortening of limbs, or internal malformations that require future surgery.

In the case of a professional in infant observation specializing in disabled infants, when he faces a family with a new baby that, for example, was born with Down syndrome,

premature or an amputee, the professional must know the different contributory factors that usually occur in situations with these characteristics. Being presented with all this information can have a dizzying effect and can occur simultaneously or interchangeably.

The different contributory factors to which I refer are 4:

The first factor I call *the special need*. This is related to diagnosis or non-diagnostic observation, with the signs and symptoms that can be seen either with the naked eye or in the test results of the clinical history. The baby is passed from hand to hand and from point of view to point of view. The child is viewed, measured, invaded, attacked, isolated, and observed (literally and clinically) by eyes that are looking for a name to call what the baby has. The "premie", as they often call premature babies in the nursery. Or after a short time, is called by his name, but always in a diminutive form, like calling him "Johnnie" instead of "John" this puts him in a place of greater vulnerability. A name gives strength and identity and is something that you carry throughout your whole life.

The second factor is what happens to the mother with that extra thing that her baby brings. And it has to do with how the image of the situation of her child changes for better or for worse. Their environment is also affected by the stress produced by the new overwhelming situation, which increases considerably, extending beyond the limits of the primary family group. The family members experience difficulties in relating to the baby; they don't know how to do it, they feel sorrow or pity, but this eventually changes or should change. Either way, each family has particular characteristics which are unique and related to disability from the personal history of each member as an individual and

the group as a whole. For example, if the grandparents had a disabled neighbor who never went out anywhere and was locked up because he behaved in an antisocial manner, it is likely that they have incorporated a distorted perception of disability, which at the moment of seeing the special need in their own grandchild, generates prejudice. These kinds of views are often present in our clinic; disability is seen as something that should be hidden.

The third is what the relationship becomes, according to these characteristics. This point is perhaps the most important because it is where you bring into play the relational dynamics between the key members of the dyad.

Everything that the parents do or don't do to move forward with their child impacts on the bond and this becomes the way in which the child is to be integrated into society. Personally I think the perception of others is enabled depending on how each mother and father views their child. Therefore, if you feel proud of your child beyond what he or she has, this fact is transmitted to the child and his environment. But if you as a parent do not feel like taking part in the struggle and you surrender instead of trying, your child will probably have that example and will follow it, giving up and becoming a difficult case to treat. From my professional point of view I believe that children who are complaining, kicking and screaming are more likely to succeed with their families than those whose flame of hope was extinguished during early childhood. This whole reality which implies accepting disability becomes a grief that takes a long internal process to resolve. It's complicated because the grief is personal, but as it reaches greater depth, it will be accepted in a better way, allowing parenting to be enjoyed.

The fourth factor is the total ignorance of the new situation and of course the deep abyss that is opened by the parents own ignorance of what to do, where to go, how to process things and how to accept or understand why, fighting questions that generate panic and face a sort of paralyzing attitude.

They don't let the baby be, because the special needs are covered in particular by the internal struggle that the mother and/or family have between what is and what should have been, between what is indicated by the professionals and their own sense of guilt: between their pain and their instinct.

These factors have to be identified and borne in mind when building a relationship with a family and their baby with special needs, in order to canal the flow, since the four factors are usually present simultaneously. But their presence is like a pendulum which swings from one to another, forcing professionals to position themselves towards the aspect that generates a greater demand, and then move to the one that takes its place and so continue.

These four components make the family rearrange and make the requirements focus on the disabled family member. There are so many items to consider, such as the effort, sacrifice and tolerance; the notion of the process; the importance of play and enjoyment of games, which becomes invisible and gets lost, and that should be given attention from the beginning of any treatment.

When a baby with a disability arrives home, it's like the four factors simultaneously come together into a large cloud that carries a list of new names and

terminology, falling like rain, extending and modifying the everyday vocabulary. This “medicalization” occurs almost naturally. The home is transformed into a hospital. Lectures, classes of medicine, games become exercises, the routine is based around a full schedule of activities and this is how parents begin to abandon their role as parents, and become pseudo-therapists of their own child, forgetting the most important thing.

It is in the early days of the new baby's life that instead of hearing words like basic care, love, future projects, you listen to terminology: early stimulation, high-risk children, early care, disability, handicap, multiple brain lesions, prematurity, multi-disciplinary treatments, surgery, intensive care, cerebral palsy; the list could go beyond the scope of this article.

All these words resonate loudly in the heads of the parents. This is going to stun them, confuse them, make them feel exhausted and tired, and that's when we should take action. Our job is to stop the bleeding from the narcissistic wound that opens for failing in the conception of a normal child, or act before the difficulty of providing a mirror where children can be reflected and thus build their own disability. To support the mother and accompany her so as not to collapse when the baby does not respond to her or does not imitate her gestures, and provide support for the emotional vulnerability that generates insecurity in the maternal role in this situation. Our task is also to help strengthen skin contact through touch that is beyond muscle spasticity, and to decompress from the head of the mother what the medical indications for child care generates in her; helping her to reduce the anxiety generated by books or from searching all over the Internet trying to

understand what the little one has, instead of devoting that quality time to enjoy it together.

Inside the mind of the mother should be a place to hold her baby, but if this mental space is filled with case reports, medical studies, multiple external challenges, and at the same time with a guilt that goes on appropriating and devouring everything in its path, her head will not be enough.

All this results in a dry and stunned breast; unable to nourish. There is no milk and no breath left, just confusion, fatigue, exhaustion. A process that should be developed naturally turns into chaos. And it is in that moment that the practitioner must provide the strings for the construction of the safety net that the mother must weave. The simple fact that the therapist is there, already provides support, but is not enough. You must also provide protection, companionship and support. Only then can the mother feel enabled and so initiate the steps for the transition to this new reality that she has to live.

The situation or condition of the child will never change more than a little, but the attitude to what is going on will change. There is a paradigm shift. Treatments last a long time and so will our professional relationship, it will not only become common, but also will be over a very long term, which will force us to see improvements and plateau periods along the way.

The experience will also bring with it positive elements. You'll get to know many people who otherwise would never have crossed your path. There will be a change in personal values. What at first is confusion and anger will come to be seen as a blessing and a challenge. All babies should be looked upon free of prejudice in order to be healthy, both

physically and mentally. Only then will we see healthy babies with Down syndrome, cerebral palsy or prematurity.

This difference between the reality and the condition is usually not so clear, but if the professional does accompany parents during the process of regaining self-esteem, after the initial emotional collapse, participation in parenting on their part will be active and the baby will be able to grow and develop happily, mainly by being accompanied and beyond being a diagnosis.

Disability is dealt with as well as the acceptance of it. The child is within a family where he can identify himself. And he looks like his father, his mother, his uncles and his grandparents. If we just think that children with Down syndrome resemble each other, or that all paralytics are equal, we are discriminating and there is no worse attack on the identity than the failure to include the child in a family. So I like to say that behind a child with special needs there is also a family with needs that are special too.

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