

**PARENTS AND PROFESSIONALS
WORKING TOGETHER**

Barcelona, 18 & 19 November 2011

Venue: Collegi Major Santa Jordi

Organizers: International Cerebral Palsy Society
European Academy of Childhood Disability
Confederation Aspace

DISCLOSURE

by Daphne Economou

The subject we were originally asked to discuss this morning from the view point of both parents and experts was “disclosure” or what we sometimes refer to as “learning the truth”. This seems to have got slightly “lost in translation” in the title of our session, but it is still the topic that I consider supremely important and, with your permission, I would like to address.

As “truth” is often a matter of opinion, I think that the word “disclosure” gives us a sounder point of departure.

Disclosure indicates the uncovering of something hidden, the speaking of something unspoken, the revealing of something unknown, which is exactly the situation that we parents find ourselves in, when we begin to suspect that there is something wrong with our newborn baby.

Seeking what is hidden, unspoken and unknown we cannot foresee what the answer will be nor can we be sure that those who answer our questions are either able or willing to tell us the truth.

So, for a start, let us ask ourselves two questions “*What do we know?*” and “*What are we prepared to know?*”. We know very little and although somewhere in our nature a certain foreknowledge regarding momentous human experiences seems to exist, it is obvious that in the case of disability in our own child, we parents have no foreknowledge or warning and this leaves us highly vulnerable and in need of urgent assistance when it does occur.

But let us begin from the beginning. A baby is born and everyone is delighted, because there is no greater joy. If there were initial problems, like a premature birth, a difficult delivery, a period of incubation, these are all forgotten once

baby is safely home. At first, everything seems normal, baby is eating and sleeping and rarely cries, but after a while, even young and inexperienced parents begin to instinctively recognize that something may be wrong. *Why is baby not reacting to sounds and light? Could she be deaf? Could she be blind? Why is she not raising her head or stretching out her hand to grasp a toy? Could there be something wrong with the function of her head and hands? Why is she not smiling or expressing some recognition of the people around her? What is wrong?*

At this stage, we parents rarely share our anxiety with one another. Instead, we keep our suspicions to ourselves and in a primitive, superstitious way, we pray that the unknown fear will go away, if it is never put into words.

The initial undisclosed elements are all there. Something hidden, something unspoken, something unknown. This is the time, when one is reminded of the beautiful words of Leon Bloy, who wrote that “*Man has places in his heart that do not yet exist and into them enter suffering and love in order that they may have existence*”.

Watching and waiting, we discover new places in our hearts through suffering and love and finally entrust our suspicions to one another.

And so the search for truth begins. Together now, we set out to discover what is wrong with our beloved baby. We ask for information and for immediate solutions, because we believe that only these can help us at this stage to face our fear, our guilt, our desolation, our terrifying vision of a dark future.

What we fall upon is a new experience for which we are again not prepared. We discover that in science there are no absolute truths and that no one has yet solved all the mysteries of nature. Because much is still unsolved concerning cerebral palsy, there are no simple answers and some parents still receive confused, obscure opinions and even conflicting views. In our quest,

we sometimes disregard our familiar and caring family physician and instead we seek out those great people, to whom we owe our major discoveries, who sometimes however are not wise enough to guard against the fanatic defense of their theories and opinions. So we find ourselves trapped in contradictions that seem to take the form of a conspiracy of unknown words: "*brain lesions, cerebral palsy, congenital trauma, motor disorder, etc. etc*". Which of these strange and threatening terms applies to our baby? Will he be labeled finally and irrevocably for the rest of his life?

In our case we were lucky, because we had a wonderful family doctor, who having seen our baby through the first 40 critical days of his life, when he was dangerously sick, was perhaps prepared for what was to come. At first he reminded us that our baby had been very sick and might still need time to recover, but when the symptoms became more evident, he very gently guided us towards the notion of what he called a "motor handicap" and he commenced early intervention with physiotherapy, so that we would not feel that there was nothing to be done. He did not discourage us from seeking expert advice in America and Switzerland, but he very skillfully kept the focus on our child's quality of life and not on ideas and methods.

So we were lucky. Yet even when ideal conditions of diagnosis and parent guidance are available, the feeling of disaster and loss may be alleviated to a degree, but the initial shock is still there.

At first reactions can become very primitive and may take the form of plain resistance and disbelief, as finding ourselves unwarned and unprepared we are praying for time, in order to better understand and better survive this terrifying new reality. Also at this stage we begin to suffer the imposition of well-wishers, who would advice and help us, with every possible recipe for remedies and solutions. So we find ourselves in the paradoxical situation of being over-advised by the unqualified and sometimes inadequately advised by the qualified. And meanwhile there are no magic cures that could make the whole problem dissolve overnight.

For every parent the components of the crisis are weighted differently. Some ask “*Why has this happened to me?*”, “*What did I do wrong?*”. Others ask “*Why has this happened to my beloved child?*”. Both questions are essentially unanswerable, because the truth is that what happens to each one of us in a crisis has more to do with our instincts and other mysterious, unconscious factors, than with our minds. We each carry our own life-form within ourselves and we must each work out our own salvation. And who to pray to? To a God, who allows such disastrous things to happen? Even to Him.

It is at this point that the experience of having a child with disability begins in its entirety. This is the experience that must be gone through, as a venture that challenges every aspect of our life and requires our total commitment. We cannot refuse our participation for only if we dare to face what is real, can we survive it. And help comes from where it is least expected, from the child itself, as often, unable to find help outside ourselves we turn toward our child and discover that he is a wonderful human being and not a medical case. And here comes the first happy break for everyone.

We discover first of all, that an exceptional human-being is a gift of nature and as such our child is a gift of inestimable value. We discover that the needs and necessities of mankind are manifold, what sets one person free is another’s prison and so it is with normality and abnormality. In our love for our child we discover that man is not a machine, in the sense that he can consistently maintain the same output of progress. He can only meet the demands of outer necessity if he is well adapted to his own inner world and to the conditions of his environment.

So we try to create a good environment in which our “special” child will be happy and consequently we begin to feel happier ourselves. We realize that all we have to do is to understand and respect the differences in our child and to guard against the futility of wishing to interpret and specify those differences. For the miracle of the child with cerebral palsy is that, although it

may lack many fundamental specifications, it still functions beautifully as a human being.

This is the best disclosure of all.

I will stop at this point, as other speakers will be taking our story forward to its next stages and because we have the privilege of passing the question of disclosure on to the ideal professional, Professor Martin Bax.