



2nd Conference and National Meeting

ALBINISM: A LIVABLE DIVERSITY

Knowing it helps to understand
sharing helps to grow up

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"I learned to dream ... And I will not stop"
The resilience: a healthy challenge for the whole family system.

Speaker: Dr. Laura Bonanni



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**"I learned to dream ... And I will not stop".
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I LEARNED TO DREAM

"I learned to dream when I wasn't a kid, I wasn't even an age.
When a school day lasted a lifetime and my world ended a little there.
Among the boring priest who gave us to do the ball was going like an engine.
There is who was unable to dream and who had already dreamt.
I learned to dream and I began to hope that those who are supposed to have will have,
I learned to dream when a dream is a cannonball,
that if you dream you kill half of it.
When you begin to understand that you're only in your underwear.
When you begin to understand that everything is bigger.
There is who was unable to dream and who had already dreamt.
Between a blow that I take and a blow that i get.
Between a friend i lost and a friend I'll have.
And if I fall once, i'll fall.
And from the ground, from there i'll get up.
There is that I learned how to dream and i will not stop.
I learned to dream when you begin to discover that every dream takes you farther,
riding kites over the walls and boundaries.
I learned to dream from there.
When all the excuses are good to play,
when whole life is a good song.
There is who was unable to dream and who had already dreamt

.....
"There is that I learned how to dream and i will not stop".

(Negrita, played by Fiorella Mannoia)

**"I learned to dream ... And I will not stop".
The resilience: a healthy challenge for the whole family system.**

With the term resilience we refer to the capacity of reaction that people have to adversity.

This term, borrowed from materials science, indicate the property that some materials have to maintain its structure or to regain its original shape after being subjected to crushing or deformation.

In psychology, resilience characterizes the ability of people to cope with stressful or traumatic events and reorganize their lives in a positive way.

What happens in a family when a child is born albino?

When things go well and that means that a correctly diagnosis it's been done promptly, we worry about the sight "issue", especially because doctors tend often to warn us too negatively, forgetting that they are facing other human beings that are emotionally and affectively involved.

My paper focuses on how to reset a **new parenthood**, a **resilient parenthood** characterized by a new structure and meaning on personal life, couple and family, since disability makes a big impact on the personal and family balance, in some cases even changing the lifestyle of the system.

Visual impairment, with its complications (nystagmus, strabismus sometimes) is not only the thing that characterize "diversity" on the child, there is the colour of the skin, so white, his white or yellowish hair, we clearly see that he's "different"! At this point we have to reckon with a new and challenging situation, **a stressful event and often traumatic.**

The good will of parents, the presence of a family contour (if there is any), the closeness of friends are not always enough.

The albino kid is "forced" to a double reorganization: one is strictly practical, logistical, made up of content, like environmental and personal arrangements for the welfare of the child (as to pay attention to the brightness of the a room, a certain apparel accessories) while the other one is going to be more "painful", characterized by a reorganization of his inner world (expectations, fears, needs,

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ideals and losses). It's the second reorganization the hardest challenge, the necessary one.

Children are influenced by the climate that adults create around them.

It's the way in which parents will be able to constructively review their inner balance that will cause, in large part, an adequate and functional development of the personality of the child of today and then the adult of tomorrow.

We are born children, we become adults.

Resilience can be seen as the strength of mind, as a construction of a frame of mind, aided by the presence of protective factors, made more difficult by factors of risk.

There are protective factors in childhood that make a person more prone to build this mental structure, factors that predispose it to cope with stressful situations, seen more as challenges than stress to avoid.

Let's look at some of them:

1. *"A good capacity of attachment to parents (or parental figures) made in the early stages of life*
2. *Cultivate a healthy imagination, creativity, daydreams*
3. *Acquiring skills, cultivate hobbies, interests*
4. *Avoid the emotional void (have at least one significant relationship), make friends, share, open up*
5. *Learn how to make sense of experiences (transitory nature of stressful conditions), prefigure positive developments (change)*
6. *Play, sense of humour*
7. *Construction of values , goals, motivations*
8. *Cooperation, interaction*

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9. *Building self-esteem, a sense of personal efficacy, (as say to yourself that you have the resources to achieve results).* " (A. Oliverio Ferraris)

Then:

***"learn to dream, begin to hope, ...
dream is a cannonball
a blow that I take and a blow that i get,
a friend i lost and a friend I'll have,
if I fall once, i'll fall and from the ground, from there i'll get up ...
you begin to discover that every dream takes you farther, over the walls
and boundaries.
All the excuses are good to play".***

There are also **risk factors**, there are those conditions which may make more difficult the way to the construction of an adequate strength of mind.

Here are some:

1. *Coming from problematic families*
2. *Serious disagreements between the parents*
3. *Very low self-esteem*
4. *Experiences of foster care (lasting more than six months)*
5. *Mentally ill mother*
6. *Delinquent father*
7. *Overcrowding at home*
8. *Children with close ages (range less than two years) " (A. Oliverio Ferraris).*

A parent sends to his/her child, more or less consciously, what he or she received by his/her parents and family-relational system. The presence of both

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risk and protective factors represents a mixed content with which they have to realistically deal.

You should make sure that protective factors are more highlighted and reinforced within the relational process, creating a **virtuous circle** that will be transmitted as a heritage from one generation to another.

It 'good to remember that this process is played at a relational level there is more non-verbal than verbal, especially in the early periods of the child's life, when, when the use of language is not yet developed and the only language is the body (vocalizations, postures, feelings, emotions).

So the central passage for the setting of a resilient parenthood is due to **knowledge**:

parents aware of their risk and protective factors are parents potentially able to educate on resilience, leading a harmonious growth for their children.

Often however, "being aware does not necessarily mean being able to handle everything that you are aware of." ("Clinical Seminars": Eric Berne Institute, M. Novellino).

Awareness is a wise teacher, prudent and soundly protective and stimulates autonomy, but at one condition: if we stay open to a honest and sincere discussion with other parents!

The informal experience of friendship with those who share the same problems related to the disability and diversity that the albino carries are certainly very important, coming into the group of protective factors that are reinforced and transmitted as a "dowry" to the children.

The forum of our website, we can say, plays a this role a little bit, as well as the meetings full of warm affectivity that take place within the associations.

But this is not enough to make a constructive awareness with aspects of real growth in the sight of a real autonomy of the child. Why?

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Often because the risk is to strengthen the discomfort, the fears, the distorted beliefs, **reinforcing a vicious circle** instead of **activate** energies to create a **virtuous circle**.

Hence the creation of mixed groups of parents to follow a real formative process conducted by a trained psychologist, is the aim to take care of the person, facilitating the emergence of personal material in an atmosphere of partnership and protected sharing, allowing big and lasting personal benefits and couple and parenting benefits too in the prospect of a healthy autonomy process of the child. What is the "golden thread" that links the process of growing to autonomy? Is the "**permission to exist**" in an unconditional way beyond any disability. Human being needs unconditional love!

**Unconditional love leaves the "if" and "but" out
and accepts the other as he/she is.**

**Unconditional love is renewed day by day through a path that leads to deal
with the ideal "I" and the ideal of "you".**

What does that mean? Each of us (carrier of a handicap or not), has a sort of ideal image of how to do things, how to solve problems, how to be a good parent, a good teacher. The ideal of "you" is closely related to the ideal of "I" because we often fantasize on the behaviour of a partner, a child, a parent. Very often the ideal "I" (what we think we are and should be) does not coincide with the real "I". Problems arrive at this point, when a preconceived image (ideal) that harks back to a model, is shattered hardly by the reality, in our case the albino son.

The ideal "I" is referred to a psychoanalytic concept. The ego ideal is a model in which an individual tries to comply. The ego ideal is formed in childhood (from 6 years to puberty) and is consolidated during the latent phase.

During the growth we slowly leave the ideal levels and we recalibrate more and more on our reality, we begin to give more executive power to our Adult,

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attributing to the "Child" and the "Parent" that are in us an adequate space and meaning. This too, like unconditional love, is a dynamic process and therefore requires knowledge, patience, trust and resilient reorganization.

The stiffening in the pursuit of an ideal model makes it difficult to tolerate doubt, uncertainty and indecision. However, these feelings are what that lead us to reflection, to rethink and then to the possibilities to implement new behaviours, different attitudes that sometimes allow us to solve, or at least unlock, interpersonal conflicts and situations that seemed insurmountable and unchangeable.

I invite you to think, now on how much "parent" there is in you, like those ways of doing things, of thinking and behaving, that were and are proper of your real parents. What ideals of family, children, partner move in your mind?

How much impact these models have had and have compared, for example, to how educate the children (in the case of parents) or how to teach the students?

And how much influence your past experiences of kids have had and have, maybe even with your parents, so now, today, you want your children to avoid some alleged "pain", because at the time you have lived them as such?

Here, everything is always been present and it is present in a much greater way when the child is born "different"!

Different than a false and distorted social model, but even more different than a model that is in our heads.

The handicap is first of all something that is constructed and "fed itself" in the head, is the "incorrect" mental posture that adults and inevitably send to: children, students, teenagers and young people.

A son or a student will be what we expect them to be.

So if we learn to know ourself in relation to our weaknesses and the flaws of childhood we lived, we will have more clarity to really see who we face, which

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(while having limitations) certainly has resources and they must be developed , reinforced, praise.

In this topic, a very special attention must be paid on a relational dynamic that can be risky in the medium / long term and can trigger a circuit:

**Saviour----- Victim----- Persecutor.
("Drama Triangle" Karpman)**

When an individual is not recognized from the capacity and expertise related to his age, "replacing" him by anticipating him, excluding him, providing solutions for him, we get inevitably and unconsciously in the role of Saviour, seeing the other as victim. This trend may continue for a long time, even for nearly a lifetime, but when the false balance is broken then the roles change and often the "designated" Victim " can transform itself into "ruthless" Persecutor by putting in some way, the Saviour in a position of Victim, indeed!

The whole dynamic process that occurs in the complete unawareness of the participants in the interaction or the chain of interactions, is characterized by some distinctive elements that distinguish it: surprise, malaise, confusion, an inner confirm about themselves, others, life.

How do we recognize that we are entering, or we risk to enter the role of Saviour in a relationship?

When we want to provide a simple and pure attempt to help a person (child, adolescent, adult) that has some real skills and abilities (commensurate with age) to ask directly for help.

In the case of a very young child, certainly we do not talk about Saving, but about a healthy and consistent care for someone who would truly be vulnerable.

**The relational dynamics characterized by down-up ratios trigger a
dangerous circuit roles:**

Saviour-----Victim --- Persecutor ,

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leaving discomfort, moodiness, feelings of failure and uselessness.

When you are dealing with a visual impairment, the residue must be fully exploited, without fear, without anxiety that something serious can happen. Certainly the use of constructive measures (aids) must be sought, but such aids should not substitute the capacity and potential of this human being.

**"Where you won't get with the eyes, you will get with the mind."
(Emanuele - from the forum).**

The mind has incredible eyes!

Allow the child, in relation to his age, to do some experiences: fall, get up, get close, get confused, find himself back and to make an effort to ask for help, not receiving it without first the need to experience it. These represent the relational-behavioural and educational modalities to stimulate the child, a **resilient mindset**: think, feel, relate and act like one who will have **strong will**.

This is the **virtuous circle** process, which will bring the child, the adolescent, the young, the adult, to feel during the lifetime "**powerful**" (conscious of having a healthy power over himself), **effective** (aware of having an impact on things knowing how to achieve goals), **joyful** (reinforcing the testing of the emotion of joy, able to signal a state of satisfaction to the body, which reinforces self-esteem).

**Power, efficiency, happiness,
possible and desirable goals at every stage of life.**

**Antidotes to the helplessness,
devaluation, fear, sadness, anger.**

"The internal representation of our diversity, whatever it is, is crucial in the construction of relationships with others." (By Forum www.albinismo.eu).

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A human being, by its own nature, is defined by a constant and continuous relational process.

Parents, teachers, educators, each adult that have a significant place in the life of a child, a teenager, a young, are responsible for much of the construction process of this internal representation. It will mark and draw the quality of interpersonal relationships of the present and of the future. Relations characterized by a feeling of being on a par with the other (I'm OK-You're OK), will strengthen the virtuous circle, while relations characterized by a gap (I'm not OK-You're OK, or the opposite, or worse like I'm not ok-you're not ok) will reinforce a vicious cycle of exchange of roles in the Drama Triangle, in an escalating alternation of helplessness and guilt over themselves and to others.

No one owe us something just for the fact that we are born with a handicap. The world is not required to "pay a compensation", to understand, to meet us with open arms and warm welcome.

The family is supposed to have important educational tasks. Teaching, with more non-verbal behaviour than words, that:

- Diversity and **limits** are present and will accompany the child for his whole life
- **You can be yourself** without shame or resentment, arrogance and sense of being a victim, learning to ask from a position of respect of self and other
- The **responsibility of one's life should be taken personally**, learning to accept no, rejections, prejudices and ignorance of others that often stems from not knowing.

These are the foundation for building a resilient personality, open to the challenges posed by life in all its phases.

"Resilience is not a condition but a process: you conquer it fighting."

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(George Vaillant)

Many parents, especially mothers, say to us in the forum, more or less explicitly, the fear of "doing mistakes".

I would therefore like to conclude my intervention reporting a good consideration made by Winnicott (British doctor and psychoanalyst, known for the theory of Object Relations):

"A mother can do and will make mistakes, but if they'll make her do better in the future, they end up turning into an enrichment."

Dr. Laura Bonanni.