



2nd Conference and National Meeting

ALBINISM: A LIVABLE DIVERSITY

Knowing it helps to understand,
sharing helps to grow up.

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**Visual Impairment: from social distress to lifestyle,
going through the school desks.**

Speaker: Isabella Macchiarulo



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Introduction.

This report has been inspired from the thesis I defended to become a professional educator, that was entitled "Visual impairment: from social distress to a lifestyle". I obviously left out those aspects of visual impairment that have nothing to do with albinism, as, for example, "the effects of partial sights in relation to the age of its arising out", because in albino subjects visual impairment is already present at birth.

Particularly, I will focus my attention on the role school plays in relation to visual impairment, lingering over those peculiar aspects that belongs to us, that is to say over a matter that takes great interest, as you can easily see from the forum albinismo.eu.

Obviously, my report is based on 36 years of albinism on my shoulders.

Some information not to take anything for granted.

Let's figure out the visual functionality as a segment: the right end, the positive one, corresponds to a correctly working visual system through which you can normally see; the left end, the negative one, corresponds to a visual system that doesn't work, through which you can't see anything, that is to say that causes blindness. Quoting mathematical rules, a segment is a part of a line that is bounded by two end points, between which you can find countless points. The same you can say when you talk about visual functionality: it may happens that the visual system is able to work, but not in the right way, causing a defective view that you cannot define as normal, but you cannot define as absent as well. That means that there is a huge range of subjects among sighted and sightless people, with different serious or less serious abnormalities of their visual functionality.

**TWO VISUAL SYSTEMS, WHICH ARE DEFECTIVE FOR THE SAME REASON,
ARE NOT EQUALLY DEFECTIVE.**

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Let's imagine to stare at a point near the left end of this segment, in order to mark off a shorter segment inside it. In Italy the same has been made to define visual functionality, particularly with L. 382/70 and lately with L. 138/01.

The first law defined three different categories of visual impairment: the Totally Blinds, Blinds with a visual acuity of 1/20 of diopter (ventesimisti) and Blinds with a visual acuity of 1/10 of diopter (decimisti).

The second law defines five groups of people with low visual acuity: the Totally Blinds, the Partially Blinds, Severe Partially Sighted People, Medium/Severe Partially Sighted People, Slightly Partially Sighted People.

I don't want to fully examine those laws, but I just want to pick out the two important changes the second one introduces if compared to the first one:

1. The appearance of the term "ipovisione" (= visual impairment)
2. The fact that the visual field has been taken into consideration as well as the visual acuity to determine if a subject can be considered visually impaired.

In any way, neither one nor the other are able to pick out the wide range of visual impairments, that cannot be standardized and cannot be completely defined.

Visual functionalities that allow somebody "**to look**" cannot be restricted only to the visus and to the width of visual field.

I used the term "**to look**", because it has a different meaning compared to the term "**to see**", although they are often used as synonymous.

When you use the term "**to see**" you are speaking of the sensorial system, that gathers and channels inside the organism the extrinsic stimulus. Since the "gathering" is guaranteed by the eye, the ability to see will be directly proportional to the efficiency of the structures that make up the eye itself.

"**To see**" expresses a function measurable in quantitative terms.

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"To look", instead, consists of a set of processes through which the individual can use the view to obtain information to actively organize their adaptive behaviours.

"To look" means to use the view to give rise to a higher order function: the **"vision"**, which can only be considered in qualitative terms, as it consists of non-measurable elements.

This definition emphasizes both the character of the intention that is proper of watching and the finalization of this particular conduct for the purposes of understanding and adaptation.

For simplicity, though not exhaustively, visual skills are: visual tracking, fixation jumps, changes of focus, perception of spatial distances, peripheral vision, binocular vision, maintenance of visual attention, visual acuity at close and at a distance, capability of visualizing images in the brain.

In the visually impaired subject, one or more of the skills listed above may be impaired, in addition to visual acuity and/or width of the visual field.

Therefore you should not wonder how a visually impaired subject sees, but how he sees. In my experience I would add that, as soon as you realize "how" a subject is able to see, you should also wonder "when" this "how" comes to fruition. We have to realize that the skills of a malfunctioning visual system, are not only imperfect, but are also unstable and unpredictable.

The uncertainty of visual impairment and albinism ambiguity.

Now it should be clear that visual impairment is permeated with uncertainty both for those who live with it and for those who observe it.

Uncertainty of visual impairment for those who live with it:

UNCERTAINTY IN RELATION TO ITS DEFINITION: I don't know when the term "ipovisione" (visual impairment) was coined and who coined it first. Anyway it is certain that its adjective "ipovedente" (= visually impaired) has been introduced in legislation only, as I previously said, in year 2001, with the enactment of the n.138/01 Law. In my experience, but surely also in your experience, it's also a

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certain thing that people who have nothing to do with it don't really know its meaning, that is more difficult to understand in comparison to the adjective "blind".

In Italian the particularity of the term "ipovisione" (visual impairment) lies also in the fact that the word is composed from "ipo", prefix that comes from the ancient Greek (that in composed words of the scientific language means "below", "lower" – see hypogeum, hypophysis – or refers to lack of something, lower degree – hypochlorhydria, hypotension) and "video", a word that comes from Latin (to have the use, or the faculty of seeing).

UNCERTAINTY OF PERCEPTUAL FUNCTION: the visually impaired subject can rely on a lacking visual function, characterized by functional restrictions, and certified by a usable, but not constant, residual vision. Specific conditions, which vary from subject to subject, such as the level of ambient light, the presence of chromatic contrast or the level of fatigue, make the use of residual vision not always possible or available at the full of its potentiality.

PSYCHOLOGICAL UNCERTAINTY: the rational awareness to have a residual vision that is unstable and therefore unreliable can induce the visually impaired subject to live with the constant fear of finding in situations where the residual sight is unusable.

UNCERTAINTY IN CONNECTION WITH ORGANIC FUNCTIONALITY: what determines visual failure can also be a cause of uncertainty. Sometimes you can have a progressive degeneration whose quickness and outcome are uncertain. Visual impairment related to albinism, however, is relatively steady through all lifetime, even if the visual system is subjected to a natural and physiological ageing, that can worsen the visual impairment degree.

UNCERTAINTY IN DEFINITION OF ONESELF: the visually impaired subjects define themselves as "not" blind and "not"sighted; they don't claim but they deny what they aren't or don't feel to be. Leaving space to uncertainty that feeds itself.

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UNCERTAINTY IN INTRODUCING ONESELF TO THE OTHERS: now a last form of uncertainty becomes clear, that is to say the effort of partially sighted people to communicate to the others the complexity of visual impairment.

If the partially sighted person introduces himself as a "sighted" subject, that is to say he does not report his visual impairment, he encounters the uncertainty in the opportunity of availing himself of his residual vision, if he introduces himself as "blind" he deprives himself of the benefits he could have from his residual vision, to avoid falling into inconsistency.

Uncertainty of visual impairment for those who observe it.

Being in front of a visually impaired person you can create feelings of uncertainty, disbelief and discomfort, because, as I said before, visual impairment is so little known, and therefore it is hard to be expected or understood.

Some people would be astonished if they were asked unexpected questions such as: "Can you tell me the street number of this house?", made from an old person who is walking quickly through the street.

These feelings often cause a lack of help from the others: helping behaviours are less common towards visually impaired people than towards blind people. Uncertainty can generate anxiety, anguish, frustration.... lack of projects, inability to dream!

The ambiguity of Albinism

As Laura said in her report, "visual impairment is not the only element that makes the difference... There is also the skin colour,...the hair,...you can easily see that it is different".

I add that it is ambiguous too, as a matter of fact we can say that albinism:

- It is clear because of the colour, but it is hidden because of visual impairment;
- It is a "sentence" (wherever you go, everyone can recognize you, even if you want it or not), it is a "salvation" (if you get lost in the crowd, it is to find you);

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- It is public, it is private;
- It forces you to protect from the sunlight that you need to survive;
- It allows you to see the people, but not your parent;

Everyone of you could add something to this list.

It is clear now that the social uneasiness of an albino could grow and strengthen, changing visual impairment into a real handicap, that is to say visual impairment can have a bad effect in the relational sphere.

What can school do for albino students?

To try to answer to this question, you need some explanation first.

If I say that "the eye is an instrument through which the brain produces intelligent strategies", only few of you would object. This is what an ophthalmologist or an optometrist would tell you, as their job focuses on the physiological development of the visual system, where the eye gathers visual information, the optic nerves carries them to the brain, and the brain interprets them.

Teachers, educators and parents must keep in their mind that visual processes develop very early in the child and lead to a complex phenomenon in which biological skills (given from physiological maturation of the body) are interwoven with mental activities (such as, for example, attention and memory) and with elements arisen from perceptual experiences.

It follows that the impairment of visual processes will considerably affect those aspects and could constitute a risk factor for the development of the self-concept, and for the subsequent acquisition of proper codes for social interaction. The visually impaired child may as a matter of fact develop attitudes of **dependency, lack of self-confidence, passivity, hyperactivity, tendency to isolation**, as a result of escaping strategies from too difficult or too anxiety-provoking situations.

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Eventually, to end with premises regarding school, I would like to highlight three aspects that can give a clear picture of the effects of partial sight on early childhood, aspects that every educator, carer, nursery operator, teacher or, simply, parent must have in their mind every time they “relate” with a visually impaired child:

1. Potential consequences of visual impairment;
2. Adequacy of experience;
3. Time Dilation.

You can successfully cope with potential consequences of visual impairment, even if they are always lying in wait, through a constant and correct stimulation of the child, to whom you have to offer adequate experiences, both for quantity and for quality; those experiences have always to keep into account the visual characteristics of the visually impaired child, and, due to the heterogeneity of visual impairment, they may not be appropriate for other subjects. To propose to a visually impaired child an adequate experience, you have to observe him continuously, so you can understand which visual behaviours he is putting into action. Another element that turns an experience into an adequate one is undoubtedly the time factor: as a matter of fact time allows the visually impaired subject to make long and repeated observations.

The importance of time factor, in the evolution process of a visually impaired child, can be noticed also in the dilation of occurrence and length of the different evolutionary stages, so that it is not so unusual that a more “alarming” development delay diagnosis is made in addition the visual impairment one.

Now it should be clear that it’s no easy to draw a profile of the visually impaired child and the fact that his visual impairment is caused from albinism makes no difference. Each visually impaired child is a special case and should be treated as such. First of all we have to learn from him, and then we will be able to help him in his learning process. What is true for every visually impaired child,

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however, is that **the visual channel, even if inadequate, remains the privileged one, but the representations of the outside world that the child perceives through it, may consist in partial, distorted or false images, and part of the real world may also pass unnoticed.**

The entrance in the school world represents for all children a crucial moment, in which the child can implement and test the relational schemes learned and carried out in the family. It is even more so for partially sighted children: implementing their reality cognitive strategies they test their effectiveness and highlight their limits.

Unfortunately teachers are not always prepared to face, educationally speaking, the presence in the classroom of a visually impaired child, neither they have the psychological tools that could be useful to contain anxiety and apprehension or to turn false hopes of their parents into reality. That's why it often happens that the teacher gives up co-operating with the family.

The first difficulty, both in order of time and importance, that partially sighted students have to face is the learning of reading and writing.

One of the most important prerequisites for achieving such learning is the ability to merge into a single "visual action" both the overall view and the "analytic/syntetic vision". With the first you look at the totality of things, with the second you can capture details. The visually impaired child realizes the fusion of these two visual forms with numerous repeated and prolonged observations of the reality. The final result is anyway imperfect, because the albino child has visual impairment both from near and far away.

It is also important to note that, when the abilities of visual recognition are steadily acquired, only a few fragments of the graphic features are enough to ensure that the figure can be recognized.

The following elements make it easy to read: the size of the font but, also the individual characteristics of handwriting, the typographic font on the printed page and on the graphical presentation, given from the contrast of text and

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background, the presence of space among paragraphs and distance of a letter from another.

The visually impaired child should be helped from teachers with specific strategies, in order to propose him in a more accessible way the world of graphic symbols, avoiding to believe that his visual performances could be “normalized” just using tools that could magnify images.

What other measures can a teacher with “a low school budget” put into effect?

- He should move the desk of the albino child as near to the blackboard as he can, without neglecting the light factor: light can dazzle, but it is also needed to enlighten what you are reading or looking at.
- If necessary, he can use a common table lamp, worth only few euros, you can find some cheap ones both neon bulbs and energy saving. The choice can vary from person to person.
- Especially in the early school years and in the learning process of reading and writing, he should use notebooks with sharp lines and more distanced rows and squares. Where can he find these notebooks? He can create them “ad hoc” with the computer. Once made the prototype, he can print and photocopy it ... you can easily download some prototypes of rows and squares papers from the website www.subvedenti.it (you can find some examples, and then suit them to your needs).
- He can use a fine or medium tipped marker (to evaluate), for example a “trattopen” to mark the line, or, simply, a large tipped pen.
- Instead of the inclined bench, he can use a simple lectern, worth a few euros.
- He should write on the blackboard only with white chalk, that offers a better contrast with the background (coloured chalk should be used only to highlight strongly).
- Books written with enlarged fonts: during the first 2 years of school they are not necessary, as books are usually printed with larger fonts. This

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service is guaranteed, for example, by the Biblioteca Nazionale dei Ciechi di Monza, but not only. More details will be given by Prof. Abba, who is attending this roundtable.

With more adequate economic resources, instead, he can dispose of the most recent technological innovation, such as:

- a personal computer;
- a table video magnifier;
- a magnifying software program, if it is possible with integrated or separated vocal speech;

If one chooses to use the computer, he has also to teach to the visually impaired child to type on the keyboard without looking at the keys. For this purpose some programs of free distribution such as "10 fingers" are available.

Last thing about helping matters: the decision to use an aid rather than another, should be taken only after careful and targeted observation of the albino child's cognitive methods and in agreement with visual rehabilitation operators, if the child attends a visual rehabilitation program.

The purpose of using technologically advanced devices should always be to make child self-sufficient in his learning and independent from any aid. For example: it is a nonsense that a visually impaired child who has a residual view that allows him to write on his own, would not do it because he is accustomed to writing with a computer. The hand-eye coordination is important and the handwriting is the clearest expression of this ability. For the same reason the visually impaired child should not be dispensed from technical/artistic/manual activities, only because he couldn't achieve great results. In these situations the quality of result should not count, but the important thing should be the effort required to get to it.

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Another important question is if an albino student really needs a support teacher while he is attending school. In connection to this, the forum albinismo.eu, in its section "Course of Study", has opened a thread in which the users of the site can express their opinions based on their own experiences. Deliberately I leave this topic open, inviting you to follow the discussion inside the forum. I only add that the support teacher is a "learning tool" that should be adopted on the basis of the albino student's characteristics and not on the basis of the deficiencies of the faculty.

Finally I would like to speak of school integration, introduced after the closure of special schools.

Those schools were large containers which included subjects with similar characteristics and eliminated any trace of individuality, uniqueness of the subject. It is not enough to deny the concept of container to remove the container itself.

The institute, what is already organized, tends to provide responses according to outdated models, which can however provide an illusory reassurance of the effectiveness of our work. A work that can be considered sterile, because it doesn't take into account the uniqueness of the subject with whom we deal and disregards that he is living a distress.

«We need to start from the bottom, meet people, walk with them, we have to interpret rules according to the new needs. Dismantling places is not enough, we must produce new contexts to prevent that "non-places" will become the fate of weak subjects. If you act in this way, the one who educate gets educated» (prof. Andrea Canevaro).

What does visual rehabilitation mean for me? It is a set of activities aimed to strengthen the residual vision and enhance its potentialities, but also to become aware of its unreliability and instability.

In other words:

"acceptance of impairment, together with a rebellion to the handicap."

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My conclusion is that a disabled person is not absolutely impaired, but is impaired in relation to the realities in which he lives, or in which he is required to live, and according to certain styles.

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Biasioli U., Cinque domande per Andrea Canevaro, Istituto Pedagogico Bologna