

ARE YOU BLIND OR BLIND?

It seems a strange query, that introduces this essay as a title. Nevertheless it contains a perfectly legitimate question that is largely overlooked or ignored in our approach to blindness and visual impairment in general and our out-reach to the visually handicapped in particular. Whenever I have to read through a report, it usually strikes me how inconsiderate we are in our ways of treatment of the problems of the different groups of visually handicapped individuals that we serve.

To begin with, we mix up our terminology and usually address all matters as pertaining to *blindness*. whereas, as has been pointed out before, the majority of visually handicapped persons are not blind but partially sighted. Some writers realize that and add here or there the expression *visually handicapped* while referring to the partially sighted, thereby demonstrating that they do so, not out of conviction, but to avoid criticism because that term indicates both the totally blind and the partially sighted. So, we have invented a new distinction: *visually impaired* but, as someone remarked, semantically speaking, this term also includes the totally blind, who can be considered *one hundred percent visually impaired*. True. But let's not be that fussy about it and agree that:

1. - **visually handicapped** will be used for both the totally blind and the partially sighted, and:
2. - **visually impaired** will be used to indicate those who still have some sight left.

The recognition that there are different groups of visually handicapped persons, does not yet imply that we have developed different types of services for them. In the past, it was common practice, that partially sighted children were simply educated as blind children in residential schools and one outstanding visually impaired young man confessed to me, that that past was not so very far behind us, because he, himself had been educated as such. As a result of the fact, that I myself was partially sighted for the greater part of my life and am now totally blind, I cannot stress enough that the *blindness* approach towards the partially sighted not only has a strong negative effect on them, but in many cases makes them shun all services labeled *for the blind*.

However, this is only the beginning of our problem! Both the group of totally blind persons and the group of partially sighted persons must be subdivided into the "*congenitally blind*" and "*congenitally visually impaired*" and ... "*adventitiously blind*" and "*adventitiously visually impaired*" respectively, that

is: those who were born blind or partially sighted and those who lost their sight, either totally or partially, in the course of their life. Why is it necessary to make these distinctions? For the very simple reason that it makes a world of a difference for a person to have been normally sighted for a long time during his or her life or not! And, then again: if the onset of blindness or visual impairment came at a very early age, or in old age or at middle age the psychological and practical implications will be completely different.

In this article, I have proposed myself to set out a number of general characteristics of the different groups of clients we have to deal with. The problem with generalizations is, however, that they tend to produce caricatures of reality. We must always bear this in mind, so that we will not fall into the trap of approaching individuals from a general vantage point. Each human being is unique and the generalized characteristics may only be used as flexible guidelines.

In the first place, we have already come to the conclusion that there is a notable difference between the congenitally blind and the adventitiously blind. This distinction is not typical for the Caribbean. What may be typical for the Caribbean (but not only for our region) is the level of protected education of the congenitally blind or, even the lack of any education, in some countries.

The adventitiously blind - who have a long lifespan behind themselves as normally or partially sighted persons -- have a completely different view of the world around them, from the congenitally blind. The adventitiously blind are the great majority, especially the elderly amongst them. The later the onset of blindness, the stronger the negative attitudes towards their own blindness and, as a result, the more difficult the process of adaptation and acceptance. This fact is never recognized (neither in the Caribbean, nor in the industrialized world) by the congenitally blind. Where there is a "*blind power*" movement, it does certainly not exist amongst the adventitiously blind.

Another important distinction which is generally ignored is that the vast majority of visually handicapped persons are not blind, but partially sighted. Amongst the partially sighted, there is a strong apprehension about joining the totally blind or even to be serviced by agencies proclaiming to serve *the blind*. As long as he or she still has some sight left, however little it may be, the partially sighted person will desperately cling to it and thereby to the world of the sighted. For him or her, total blindness is often more of a monstrous menace than for a normally sighted person and such an evidently important thing as preparing for total blindness in the case of a progressive condition, is virtually non-existent, because the prospect of total blindness is rejected.

The main characteristics of the congenitally blind -- in so far as general characteristics may be attributed to them in which case we must allow for the exceptions that confirm the rule -- are:

- - 1 a limited view of the world and society, as a consequence of a very limited perception of their environment. It is in fact impossible for somebody not born blind, to fully understand the way in which a congenitally blind person perceives the world and the congenitally blind person him self cannot explain his way of perceiving things because he does not understand what visual perception means.
- - 2 as a consequence of 1. a congenitally blind person has a sense of what we could almost call self-imposed *apartheid*, of standing apart and alone in society.
- - 3 as a consequence of 2. a congenitally blind person has a strong desire to group together for the protection and defense of their own little world.
- - 4 the congenitally blind who have had a good or reasonable level of education, contrary to the adventitiously blind usually display great independence in their behavior; a lone blind traveler, will usually be a congenitally blind one.

The adventitiously blind (i.e.: those who have lost their sight in the course of their adult life), form a very complex group, which we could subdivide into three main ones:

- 1: juvenile adventitiously blind persons;
- 2: middle age adventitiously blind persons;
- 3: elderly adventitiously blind persons.

The only general aspect that distinguishes them strongly from the congenitally blind, is that they know what the world looks like and what sight really means to a human being. which entails great advantages, but at the same time great disadvantages. For instance, whereas the congenitally blind move around relatively easily, in spite of their very limited knowledge of environment, the adventitiously blind, especially the middle aged and elderly amongst them, will seldom venture to travel alone.

If the onset of blindness came at a very early age, say, before age six or seven, these juvenile adventitiously blind persons will usually display the same kind of behavior and attitudes as the congenitally blind, although they do not have any strong *blindisms* in their behavior. *Blindisms* have their origin in the early years where the child starts stimulating itself for lack of visual stimuli from outside.

It is well-nigh impossible to generalize any characteristics of the juvenile and middle-age adventitiously blind, because the various ages of onset and therefore the longer or shorter period of life experience and professional and social skills determine to a great extent an individual's behavior and attitudes. For the elderly adventitiously blind, -- by far the largest group of blind persons, a fact that is generally ignored! we can categorize some general characteristics, again with the restriction that all generalizations must be treated with great caution.

1. - After the mourning period has passed more or less, most elderly blind persons remain with a sense of incapacitation and loss of self-worth.
2. - as a consequence of A. the elderly adventitiously blind often display an attitude of undisputed acceptance of any thing others will do for them whether good or bad;
3. - as a consequence of B. the elderly adventitiously blind often retreat to an inactive existence without the will to overcome their handicap.
4. - as a consequence of C., they often lose their sense of usefulness and as a result the will to live or, in many religiously inspired cases, they may indulge in abandonment to suffering or in waiting for the miracle to happen.

MAJORITY

The partially sighted are again a completely different group in which both the degree of partial sight and the age of onset of the impairment determines their attitudes and behavior, but, even the so-called *legally blind* amongst them, usually refuse to be considered part of the group of blind persons while the world of the normally sighted, to which they pretend to belong, does not accept them as equals. Within the group of visually handicapped people, the partially sighted are by far the majority, but that is a fact not recognized by the majority of blind persons and certainly not by the congenitally blind, or if they recognize it, they ignore it, let alone, that their specific interests and problems receive the attention that they deserve on the basis of their numbers.

If it was already very problematic to try and categorize the specific characteristics of the adventitiously blind, the diversity amongst the visually impaired entails even greater obstacles in that respect. We are not only confronted with a group of congenitally partially sighted persons and a group of adventitiously partially sighted ones but also with an almost infinite variety of low vision problems. The term *low vision* is also one of those flags that doesn't cover the cargo altogether. Some visually impaired persons have excellent visual acuity but practically no field of vision, whereas others prove that they are capable of such intense use of their limited sight that they surpass normally sighted

persons in their visual achievements. Sight, after all, not only depends on the higher degree of perfection of the external organs -- *the eyes* - but also and very strongly so, on our brains' capacity to interpret the visual images transmitted to them.

One thing can definitely be said about the visually impaired in general and it has been said before, not only in this article: *low vision clients are not blind and should not be approached as blind and should not be serviced as blind*. Their diverse needs for low vision training and low vision aids should be addressed as low vision services! Low vision services are just as important as rehabilitation services for the blind, or even more so if the total numbers of clients play a role. But that should not be a criterion, since we have to direct our services upon individuals, upon the specific needs of each one of them.

In conclusion, we may cautiously try to classify some general characteristics of the partially sighted, such as:

1. - a partially sighted person is more problematic as a rehabilitation client than a blind person, because he will, almost always, over-estimate his own visual capacity (with the exception perhaps of the elderly adventitiously partially sighted).
2. - a partially sighted person with a progressive condition, will, as a rule, not be prepared to adjust in advance to his eventual blindness until there is no way out for him or her any more.
3. - a partially sighted person, who loses his sight completely, often has to go through a deeper mourning process than a normally sighted person. Sighted and blind rehab workers should be very much aware of this and usually are not.
4. - a partially sighted person often makes a fool of himself by pretending to see more than he really does. He will not easily use a white cane, even if he badly needs it as a traffic signal.

EVIDENT ANSWERS

One doesn't have to be a psychologist to be aware of these simple facts. And yet, -- it cannot be stressed enough! -- these simple facts are very much ignored. Let's ask ourselves what we really want

with our services. The answers are so evident, that we do not have to mention them. So, let's act upon them!

[published in the June 1987 edition of "Caribbean Vision".]