

SOCIAL STIGMATIZATION IN ACHONDROPLASIA

Document prepared by Saulo Fernández Arregui for ALPE Foundation

SOCIAL SITGMATIZATION

A social stigma is defined as an attribute that distinguishes a person or group of people over another and that in certain social contexts implies the devaluation of the person in the eyes of most members of the dominant social groups. The stigmatized person carries itself a high risk of being a victim of discrimination, social exclusion and ostracism.

There are many types of social stigmas: for example, in many Western countries where the population is mostly of European origin, dark skin, Latino, Arab, African, Asian, Gipsy, etc. remain a powerful brand that devalues right away a person in the eyes of others. Being a woman is, in some circumstances, a source of a very powerful social stigmatization. In contemporary societies, being a woman is still an attribute that, for certain issues, has negative implications.

The social stigma is contextual. Today in elite sports context in the United States, for example, being black has no pejorative implications, on the contrary. However, in the context of high finance, law or politics, being black may involve a strong social stigma. Similarly, a woman can ease the task of finding a job as a kindergarten teacher or psychologist, but can easily become a stigmatizing factor in the field of industrial engineering, policy or business management.

SOCIAL STIGMATIZATION IN ACHONDROPLASIA

Achondroplasia is a source of social stigmatization. Having achondroplasia means not always solely to be different from others or have certain medical or physical accessibility problems. Being small and have characteristic physical features of achondroplasia is perceived in many social contexts and by many people as a pejorative characteristic, and this has extremely serious consequences for the life of the person affected at all levels.

Since March 2006 we are working for the research project by the Department of Social and Organizational Psychology from the UNED Psychology Faculty on the psychosocialconsequences of stigma associated with achondroplasia. Following this study we proved the following questions:

1. Perception of the depreciation and stigma

People with dwarfism realize from a very early age that others see and treat them as not only physically different people, but as people of lower social status or identity. Since the first moments at school, that colleagues of children with achondroplasia are surprised that they are in their class "because they are so small" and ask them about, for example, why they don't use diapers or why they aren't carried in a baby stroller. Also from a very early age a child with achondroplasia and other forms of dwarfism is aware that is being observed in an indiscreet way by strangers when they walk in the street, and these looks are often accompanied by derogatory or burlesque comments. As they grow, the "capacity" people with dwarfism have to attract the looks of other people increases, as well as derogatory comments.

From early age, the person with dwarfism realize on many occasions that others treat him/her disrespectfully, devaluing the identity as a person. Often they realize they are disregarded in social interactions or social activities. All this undermines the person's psychological well-being and its growth opportunities at the professional level, training and personnel.

2. The stigma in the school context

At the school context, it is very common for people with dwarfism to realize that many of the other children do not have them in consideration as an equal when it comes to relate to them. People with dwarfism are often excluded from school and extracurricular activities for physical reasons (in tours, for example, or during sports activities, whether in physical education class or voluntary physical activity). Often, people with dwarfism are also teased at school, get insults and offenses related to their condition, leading to exclusion and ostracism for reasons of personal identity (regardless of physical ability). In some cases, provocations and humiliations come from a small group of colleagues. If this is the case, it is easy to underestimate the seriousness that these insults have for the particular person. Teachers often try to support the child saying that the people that insult is a minority and are isolated cases. However, even when it's just a colleague insulting the child with dwarfism, when the insult is related to the object of stigma (dwarfism or different physical appearance), the damage to the affected person is always much bigger than any insult unrelated to the object of stigma. This is because an act of disrespect towards the person object of stigma highlights the identity of the person vulnerability to others, pointing out for the person in concern, that for many others, he/she has little value as an individual. It is common, moreover, that the insults and offenses that begin from a minority, to generalize. In these cases, the person object of stigma becomes the centre of harassment and contempt to other colleagues leading this person to a situation of complete isolation. It is also common to occur cases, related with dwarfism, known in social psychology as "stigma by association".

Stigma by association is produced when a person without stigma realizes the drawbacks of stigmatization by itself when is near a stigmatized person. This feeling causes the desire to not approach the stigmatized person or not to seat beside her in social situations, which further deepens the risk of ostracism and social exclusion of people with dwarfism.

3. The indirect consequences of stigmatization: the depreciation of identity and the threat to the need to belong.

All these experiences are accumulated in the early years of one's life. The message that the affected person will internalize is that his body and person, it is for other people and in many contexts, less valuable, not only in a purely physical level, but this depreciation also affects his identity. This finding has, as a rule, a fundamental consequence: the person with dwarfism feels socially vulnerable, or in other words, understands that his need to belong is threatened. The need to belong is defined in psychology as a basic and universal need of every human being to belong to groups and social networks. When a condition as a stigma threatens the inclusion of people in social groups, there are a number of well documented effects on psychosocial literature. The effects that stand out are: apathy, lack of motivation and emotional blockage. The stigmatized person realizes the rejection by the other, and the causal reason, and the person wonders about the possibility of being a full member of the community where he/she live. This person becomes very sensitive to signs of rejection and often works almost obsessively for the list of possibilities with others and the value that others give to his identity. This concern, apathy and discouragement, which tend to arise as a result of perceived threat of belonging, along the associated emotional block, impair school performance. It's frequent to have cases of people with dwarfism suffering a blunt academic failure due to the consequences social stigmatization

Another obvious consequence of the person who perceives that is being stigmatized is the fear of exposure in social contexts that could potentially produce rejection and exclusion. For a young person with dwarfism to get out, go to places of leisure, this usually involves more effort than for people without stigma or without a stigma as obvious as dwarfism. The reason is not the accessibility, but the vulnerability to the looks, stares and comments from other people that might remember that person his/her state of stigma.

It is also often the fear of moving into new contexts (such as changing from primary to secondary school or from college or school to the workplace). The person with dwarfism often recognizes the concerns facing social contexts of this kind for the first time and, often, this fear is solved avoiding these contexts.

4. The direct consequences of stigmatization: work discrimination.

The psychosocial disadvantages associated with a stigma, such as achondroplasia or dwarfism, are also typically direct: there are many instances in which, other people leave out

or discriminate a stigmatized person. The most obvious occasions of discrimination are those that arise in a work context. People with achondroplasia do not receive the same employment opportunities than people without dwarfism, even with equalization in other variables such as education achievements, age, sex, etc.

Many people with dwarfism are called for a job interview after evaluation of the *curriculum vitae*, but they are rarely hired, when the interviewer becomes aware of the dwarfism. At the time of being promoted on merit in his/her work, discrimination is evident.

All these issues have a profound impact on the psychological well-being of the person in concern. A person with dwarfism has to face throughout his/her life barriers often huge due not only to their physical limitations, but above all, the limitations resulting from the devaluation of their identity by another as a result of their condition.

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