

TRANSCRIPTION

MOT À MOT

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SUJET : DISCOURS DU DOCTEUR BENEDETTO SARACENO À LA CONFÉRENCE OPS/OMS SUR LA DÉFICIENCE INTELLECTUELLE.

MICHAËLLE JEAN (ANIMATRICE) :

Merci beaucoup, Monsieur (...), thank you very much. Au tour maintenant du Dr Gaston Harnois de nous présenter le Dottore Benedetto Saraceno, directeur du département de santé mentale de l'Organisation mondiale de la santé.

GASTON HARNOIS (PRÉSIDENT, COMITÉ ORGANISATEUR) :

I first would like to thank Mr. (...) who just spoke to us, and indicating ways in which the OAS and the commission, the two chairs, might be useful in... for us to promote the value of the declaration and how we could improve, put forward and increase consideration of rights for people with intellectual disability. C'est à ce moment un grand plaisir pour moi de vous présenter un bon ami, un grand ami, le Dr Benedetto Saraceno. Le Dr Saraceno est un homme qui est un homme de principe, c'est un homme d'action et c'est aussi un homme de vision. Je commencerai par vous dire que ce matin, il était à son bureau, à Genève. Ce soir, il est avec nous. Vendredi matin, il sera à son bureau, à Genève, et vendredi soir il sera à Moscou. Donc, ça en dit assez long de l'estime qu'il porte à la cause que nous défendons aujourd'hui qu'il se soit déplacé pour 24 heures pour venir à Montréal depuis Genève avant de retourner à Genève-Moscou. Le Dr Saraceno a eu une carrière brillante. Il est, comme son nom l'indique, tout à fait italien, de la région de Milan. Il est psychiatre. Il a occupé un poste très important du laboratoire d'épidémiologie à l'Institut Mario Negri de Milan pendant une dizaine d'années. Et je pense qu'après avoir... Et il a aussi collaboré de façon très étroite à la réforme des services de santé mentale dans son pays, réforme qui, comme tous ceux qui s'occupent de santé mentale le savent, fait encore école à travers le monde aujourd'hui. Et il a été, après avoir fait ce travail en Italie, il a très facilement senti l'appel du niveau international. Nous avons eu le privilège de le retrouver comme président de l'Association mondiale de réadaptation psychosociale pendant trois ans, où il a fait un travail admirable. Et après coup, quand le temps est venu de trouver un nouveau chef à la division de santé mentale à l'OMS-Genève, son nom s'est imposé assez facilement. Il y avait... Il y a toujours, évidemment, des postulants pour ces postes prestigieux que représente celui de la direction de la santé mentale, et le Dr Benedetto Saraceno a été choisi à toutes fins pratiques assez facilement comme étant le candidat idéal pour diriger un peu les grandes idées de ce que l'OMS devrait faire en santé mentale et aussi dans les

secteurs connexes, alcoolisme et incapacité. Et c'est à ce titre le responsable, si vous voulez, du secteur de l'incapacité, de la déficience intellectuelle au niveau de l'OMS, à Genève, qu'il va s'adresser à nous ce soir. Donc, nous lui sommes très reconnaissants d'avoir accepté de venir nous rencontrer et je lui cède immédiatement la parole. Benedetto?

(applaudissements)

BENEDETTO SARACENO (DIRECTEUR, DÉPARTEMENT DE SANTÉ MENTALE, OMS) :

Bon. Bonsoir. Merci, Gaston. Un grand ami, le responsable du fait que j'aie commencé ma carrière dans le domaine de la réhabilitation psychosociale. Il était président avant moi. Monsieur le ministre, chers amis, *compañeros de Latino America*, let me use the official language of the WHO - one of the official languages of the WHO -, which is English. Persons with intellectual disability form a distinct group from persons with psychiatric illnesses, but both share stigma, discrimination, human right violations and an excessive influence of biomedical models. In many countries, both mentally ill and mentally disabled share the same shameful asylums. Intellectual disability, disease, no; illness, no; disorder, impairment, disability, condition, problem... This very important terminology debate should not hide the fundamental question, which is, "What are the paradigms that make intellectual disability a condition where fundamental rights are violated and fundamental needs are ignored?" As a conclusion of WHO global activities over the last four years, we have learned interesting lessons when providing policy assistance in countries. To summarize these lessons, we may say that the equation "resources plus technologies" to be equal to "quality" is not true, because it requires much more variables to be true. In fact, a number of paradigms may influence the quality of services, in spite of the difference in resources and technologies. These paradigms are independent of resources and technologies, but make resources and technologies more or less powerful and effective. Let us examine three paradigms we have identified among others that are in a way relevant to the issue of intellectual disability.

Paradigm number one, exclusion versus inclusion. The exclusion approach is not focused on people, experience and need, but rather on the environment's perception and needs. This approach results in an overemphasis on security or on incapacity issues, including an overestimate of dangerousness or of disabilities of people. In the WHO, we have noticed that systems where security and incapacity preoccupations prevail are generally of worse quality than those where user's understanding is prevailing. When social organizations are vertical, the State is prevailing through a closed system of values, they tend to invest in control rather than in inclusion. Usually, these social organizations identify exclusion with large institutions. On the other hand, when social organizations are horizontal and the State is less prevailing, they tend to organize exclusion in diffused institutions where, *quand même*, institutional logic and ruse remain, in spite of the absence of visible walls: homelessness or abandonment to a wild, private system of care with no quality control. On the contrary, when a social organization starts addressing people's needs and looking at his, her disability without denying the people's enjoyment of full citizenship, the necessity of exclusion decreases. Shifting the paradigm from exclusion to inclusion has obviously enormous consequences in terms of shifting investments from medical models - for example, hospitals and beds - to psychosocial support and communities.

Paradigm number two, short-term care versus long-term care. Health systems are conceived and organized, very often, to respond only to acute conditions - hospital model. After the acute

phase is resolved, the users enter a confused and confounding limbo of infrastructures, of human resources, of skills, of responsibilities; quite vague, quite smoky. The key question instead is how the entire health system can serve the needs of people when they require long-term support. And this is not just for mental disorder, not just for disability, but for many chronic conditions requiring long-term care: HIV-AIDS or tuberculosis, for example. Indeed, the medical, institutional temptation is there, as the simplest and the most devastating answer for long-term care or rehabilitation. We need a radical shifting, from models centred on space location of the provider - the doctor, hospitals, clinics - to a model centred on time dimension, not of the provider, but of the user. Health systems tend to put resources and competencies in places suitable to doctors, namely hospitals, where short-term care is provided and long-term care is ignored. As a consequence of that, a parallel system is created, which is characterized by poor resources, poor competencies. Instead, long term should imply means and strategies much beyond those associated with a medical model. We need diversity in people, diversity in competencies, in places, in social actors. Comprehensiveness becomes the keyword. Taking long term seriously and avoiding shortcoming institutionalizations or abandonment requires a serious analysis of the real, natural and social history of longstanding and disabling conditions.

And this leads us to the third paradigm: biopsychosocial approach versus biomedical approach. In 1977, Engel - not the friend of Marx, but the American psychiatrist - in a historic article published in *Science*, coined the expression, "biopsychosocial" to describe the need in medicine for a new paradigm that would go beyond the traditional biomedical and reductionist model. Today, the adjective "biopsychosocial" is frequently used to define what is supposed to be an integral approach to medicine. However... however, it has become progressively more meaningless, ritualistic and shibboleth. This schism between the ritualistic use of holistic notions and the practice of medicine, which is still strongly oriented towards the biological paradigm, is particularly evident in the field of mental health. As opposed to psychiatry, mental health is a discipline intended as something far more complex, which considers the psychological and social dimension of health and the psychosocial factors which determine mental health and illness. We must keep the holistic approach used to mental health also for mental disorders, also for disability. Today... today, mental health systems seem to be strongly conditioned by the biomedical model. The reason of that should not be searched for in a theoretical resistance on the part of professionals towards the innovation caused by more holistic approaches. The real issue rests in the cultural, social and economic resistance to the consequence that the biopsychosocial approach causes, or rather *would* cause, in policies and in organization of services. In fact, to shift from a biomedical approach to a biopsychosocial one would cause fundamental changes in the formulation of mental health policies, in financing of mental health programmes, in the daily practices of services and in the social status of physicians. Such changes would imply the recognition of the role of users and families, the recognition of the role of the community not just as an environment, but as a generator of resources that must go hand in hand with the resources provided by the health services, and finally, the recognition of the role of sectors beyond health, like social security, social assistance, welfare and the economy in general.

At this point, it is important to clarify, once and for all, that the conflict between the biological, psychological and social approaches is in itself a false conflict; I would say even a stupid conflict. The real conflict exists and grows inside the medical model of human development. The medical paradigm, apart from its major... mi... major, minor concessions to the contribution of psychology and sociology and human sciences, pervades all of psychiatry and tries to pervade the mental health culture as well. It goes beyond the boundaries of medicine,

pervading human life problems and suffering, fragmenting problems and demands, constructing fragmented answers. The psychosocial dimension of disability should be - *must* be - an intrinsic component of service provision and not just a concession in etiological modelling. The social dimension of health requires a social dimension of service provision. Neurosciences have provided an extraordinary contribution to understanding the brain, but very, very few practical solutions. This statement has dramatic implications, because the emphasis of intervention should be moved from symptoms to functioning and disabilities. In other words, the real question is not whether professionals believe in the biopsychosocial or not - it's totally irrelevant to know what they believe - but rather if the services are really organized to put into practice a biopsychosocial approach, which means services equally concerned with the disease and disability of their users as with their citizenship. Complete and aware citizenship and mental health are tightly connected and a deficit in one implies a deficit in the other. An individual, or a group, which does not enjoy full citizenship is at risk for mental health, just as much as an individual, or a group, with poor mental health, is at risk for the full enjoyment of citizenship. Too often, mental health services are reduced to provide biomedical treatment in hospitals for short periods of time, on the one hand, and on the other, miserable, separated rehabilitation services provide isolated baskets of generic welfare interventions. The lack of the social dimensions leads to inappropriate, long-term care provisions, entertainment instead of rehabilitation. Psychosocial rehabilitation is not entertainment organized by underpaid staff or by specialists in the most bizarre techniques. It is the reconstruction of citizenship through everyday-life skills. Rehabilitation requires interdisciplinary and intersectorial strategies and alliances.

In conclusion, the biomedical model is becoming a colonizing paradigm, framing human suffering into a biomedical frame. This leads to a proliferation of artificial, separated identities. I'm amazed by the growing number of associations labelling themselves with psychiatric diagnostic categories: the subject disappears, imprisoned in their mono-identity definition. The extension of this biomedical model to human suffering is leading to artificial identities, which *de facto* deny the complexity of psychosocial determinants. Refugees, women-beater, people exposed to war become just clinical categories, and these become their main identity. And where is gone the richness of the multiple identities that exist in each individual? What should be done in order to lose... not to lose such richness? Why do people, instead of being forced into one identity - you are a depressant - cannot be, instead, singularities without identities? When one single identity captures a person, this person becomes an inmate of an institution. Deinstitutionalization means a process much more complex and comprehensive and intelligent than just discharging patients from hospitals. Deinstitutionalization means getting free from the institution represented by the category "mentally ill." People are much more deprived by the discriminatory decision of labelling them with one - and only one - category than by the disability *per se*. We have to deinstitutionalize the fictional identities, empower the richness of identities, reconstruct the history of individuals that are all different and all full of a variety of identities. We should work for the reappropriation of the singular sense that every person produces. We should put more emphasis on the notion of citizenship. It seems to me very much possible that the need of pertaining to one - and only one - identity is inversely proportional to the degree of enjoyment of full citizenship. By solely one identity, one can die, or one can kill. We need citizens carrying their disability, rather than disabled carrying their citizenships. The pharmaceutical industry seems delighted to support separated and isolated groups of people whose unique identity seems to be a specific disease or a condition. On the contrary, the World Health Organization considers that people's main identity should be as citizens enjoying the fullness of their rights, whatever could be the condition from which they suffer. In 2001, the WHO made an exception to its usually politically - and somehow empty - correct language,

saying, "Stop exclusion, dare to care." The World Health Organization recognizes exclusion of people with mental disability as a universal phenomenon to be fought. Fighting exclusion is a precondition for care and for rehabilitation. No credible care, no credible science can be framed within exclusion. To do so, we need to build up a network of knowledge, people, institutions, otherwise we will offer simplistic answers to very complex questions. Why? Human suffering is not linear, why should the response be linear?

Monsieur le ministre, je vous prends à témoin pour m'engager personnellement et pour engager le département et le programme de l'OMS de santé mentale à prendre la déclaration de Montréal et la faire vivre dans le sens de la *implementation, dissemination, promotion and fight*.

(applaudissements)

L'Organisation mondiale de la santé n'a pas su être à l'avant-garde dans le domaine de l'*intellectual disability*. On a vécu avec et on n'a jamais pris une position claire. Cette fois, c'est la société civile qui a pris la position nette et claire et qui a obligé ces grandes organisations, comme les organisations que nous représentons ici ce soir, à se demander si elles voulaient ou non être ce soir à Montréal. Et donc, ça valait la... le coup et la peine de prendre l'avion pour être ici et pour témoigner que l'OMS est ici. Bonsoir.

(applaudissements)

GASTON HARNOIS (PRÉSIDENT, COMITÉ ORGANISATEUR) :

Je ne sais pas pourquoi c'est moi qui prends la parole. Ça devrait être un des représentants qu'on a eus hier et qui parlaient si éloquemment malgré les problèmes que la déficience leur imposait. Donc, en leur nom, Dr Saraceno, en notre nom à nous tous qui avons travaillé et produit cette déclaration, nous allons essayer de relever le défi que vous avez aussi lancé à notre propre ministre, ici, au Québec, pour faire en sorte que cette déclaration soit actualisée, soit nourrie, soit mise de l'avant et que dans les années qui viennent, on puisse dire que quelque chose aura changé. Je vous remercie.

(applaudissements)

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