



RETHINKING HIV INFECTION AND OTHER CHRONIC EVOLUTIVE PATHOLOGIES (CEP) AS SOURCES OF DISABILITIES AND RIGHTS HOW TO DEVELOP THE POTENTIAL OF RECENT LAW AND CONVENTION ON DISABILITY TO IMPROVE SOCIAL ASSISTANCE AND ACCESS TO EMPLOYMENT FOR PERSONS LIVING WITH HIV (PLHIV)

M. de Montalembert, C. Kapusta-Palmer, D. Quantinet, S. Hamamah, <u>M. Celse</u>, L. Geffroy, W. Rozenbaum (National AIDS Council)



IMPROVEMENT OF THE HEALTH OF PLHIV CONTRASTS WITH THEIR DIFFICULTIES WITH EMPLOYMENT

THANKS TO HAART:

- Jife expectancy and quality of life have improved spectacularly
- → PLHIV have a new faith in their own future
- they may continue to work , or return to professional activity

HOWEVER:

- → access to, maintenance of, or return to work remain difficult for many PLHIV:
- → HIV acts as an amplifier of initial social difficulties.

Employment rate for general population in France 65 %

Standardized employment rate for PLHIV

- diagnosed before 1994
- 49 % 59,3 %
- diagnosed since 1994 5

The employment rate is influenced by duration of infection and socio-demographic criteria including gender, country of origin, education, and initial social situation

(Source: Vespa Study, 2003 data for France)

HIV UNDERMINES PROFESSIONAL CAREERS:

- revealing one's pathology remains dangerous: stigmatisation, discriminations (hiring rejection, loss of job, sidelining within the workplace, obstacles to career development)
- most PLHIV conceal their pathology
- > concealment may also be risky: psychic distress, behaviour that compromises observance or medical follow-up.
- incapacitating effects of the infection and/or treatments, and their repercussions on professional life, are not sufficiently taken into account.

BROADER DEFINITION OF HANDICAP MAY IMPROVE OUR RESPONSE TO THE NEEDS OF PLHIV AND OTHER CEP: THE POTENTIAL OF THE NEW FRENCH LAW

THE NEW FRENCH LAW ON DISABILITY:

- → is in line with the spirit of European and international recommendations on disability
- breaks with the traditional image of disability, limited to immediately visible physical or psycho-motor handicaps
- > widens the notion of disability to include all types of incapacitating consequences of chronic illnesses
- conceives of disability as resulting from a poorly adapted environment rather than as residing in the deficiencies of the disabled person
- Setablishes the responsibility of the wider society to insure that the disabled person has access to all sectors of social life, including a harmonious professional life

THE LAW THUS POTENTIALLY MAY PERMIT:

- the incapacitating effects of HIV to be conceived as disabilities
- > better use by (and for) PLHIV of existing measures to encourage the employment of disabled persons
- \rightarrow adaptation of such measures to the specific needs of PLHIV and other CEP

BUT THE LAW ALONE IS NOT ENOUGH TO CHANGE PRACTISES. WE NEED:

- \rightarrow to shift images of disability, and of HIV/AIDS, in all the sectors involved
- to sensitise the actors of measures and mechanisms regarding disability to these new forms of handicap, and adapt them accordingly
- > to improve the ways in which mechanisms for workplace health deal with the effects of HIV and CEP

THE CNS RECOMMENDATIONS

IMPLEMENTING THE NEW DEFINITION OF DISABILITY REQUIRES:

- that PLHIV and actors in the fight against AIDS take on board the opportunities presented by the new definition of disability, and promote their rights within the traditional disability sector
- that the disability sector opens to these new forms of disability

The law of February 11, 2005 stipulates that

"A handicap is constituted by (...) any limitation of activity or restriction of participation in the life of society suffered in his or her environment by a person because of substantial, durable or definitive impairment to one or several physical, sensory, mental, cognitive or psychic functions; a polyhandicap; or a disabling health disorder."

For more information on this subject, consult

Opinion and recommendations on integrating persons living with HIV into public policies on disability

National AIDS Council, September 10, 2009

www.cns.sante.fr/spip.php?article312&lang=en

Contact: michel.celse@sante.gouv.fr

- that the authorities sensitise public opinion to the new concept of disability
- that bodies in charge of disability develop mechanisms for assistance and guidance that are better adapted to the characteristics of CEP, particularly the variability of their effects on health.

REGARDING EMPLOYMENT, WE SHOULD ALSO:

- fight prejudice and discrimination in the workplace
- sensitise and train workplace actors (employers, unions, workplace health services) to the difficulties encountered by employees confronted with illness and disability
- In encourage employers to develop innovative solutions to adapt the workplace and/or modify job schedules, the pace of work and performance expectations for persons suffering from CEP.

The French National AIDS Council (Conseil national du sida, CNS) is an independent, consultative French agency that was set up in 1989. It comprises 24 members: specialists working in the field of HIV/AIDS, representatives of civil society, and members of associations.

The CNS delivers opinions and recommendations on the full spectrum of issues that society faces as a result of HIV/AIDS. These papers are addressed to the French authorities and to all those involved in or concerned by the epidemic.

It is the intention of the CNS to participate in this manner in the development of public policy, within a framework that promotes respect for fundamental ethical principles and human rights.

For more information, you are invited to consult our website: <u>WWW.CNS.SANTE.FR</u>

CONSEIL NATIONAL DU SIDA | 39-43 QUAI ANDRE CITROËN | 75902 PARIS CEDEX 15 | France | T. 33 [0]1 40 56 68 50 | F. 33 [0]1 40 56 68 90