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# HIV, EMPLOYMENT AND DISABILITY: OPINION AND RECOMMENDATIONS ON INTEGRATING PERSONS LIVING WITH HIV INTO PUBLIC POLICIES ON DISABILITY

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**OPINION AND RECOMMENDATIONS ADOPTED BY THE NATIONAL AIDS COUNCIL IN PLENARY SESSION, SEPTEMBER 10/09/2009.**

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# HIV, EMPLOYMENT AND DISABILITY: OPINION AND RECOMMENDATIONS ON INTEGRATING PERSONS LIVING WITH HIV INTO PUBLIC POLICIES ON DISABILITY

Progress in treating HIV infection since the arrival of highly effective multi-therapies in the late 1990s has radically altered patients' lives and future prospects. Initially a disease whose onset was deferred but whose evolution was unfailingly fatal, HIV infection has evolved, thanks to these treatments, to become a more chronic condition: when it is treated correctly, and, most importantly, in a timely manner, patients' life expectancy can return to near normal. Returning patients' life-spans to more normal durations poses new questions regarding the professional activity of these persons. Despite spectacular improvement in their state of health, a significant proportion of persons affected by the epidemic continue to confront major difficulties regarding access, maintenance or return to employment. For these persons, who may be temporarily or durably at a distance from employment, recourse to the various compensatory mechanisms of the national system of social welfare (and notably to measures benefiting disabled persons) remains the rule.

Responding to a request from Sidaction, a non-profit group that is a spokesman and fundraiser for various non-profit bodies involved in accompanying and assisting HIV-infected persons in their social and professional integration, the National AIDS Council has decided to initiate an analysis of the nature of the obstacles that prevent persons affected by the epidemic from returning to full activity, and how best to lift those barriers.

This analysis of the obstacles to activity implies scrutiny of the repercussions of HIV infection and its treatments on the health of the persons affected, and the ways in which they may impact their social and professional lives. Too often, the incapacitating effects of HIV -- which may not be immediately apparent, but which can be genuinely disabling -- are underestimated or ignored. It also entails analysis of society's image of the disease, which remains highly stigmatized and difficult to discuss, forcing patients to conceal their HIV status. Finally, it involves deeper investigation of the difficulties they encounter as users of a system of care and welfare that is not only complex but which can also prove to be poorly adapted to the specific characteristics of these patients' pathology and experience.

In order to improve the welfare system's care for persons living with HIV, and rethink the constraints of the disease in terms of employment, society's outlook on the people it affects will need to change. The reform mandated by the law on disabilities that was promulgated on February 11, 2005 provides the basis for a new conception of this outlook, and the Council wishes to construct its recommendations within the perspectives potentially opened by this law. Beyond the specific case of HIV infection, these recommendations should be seen as a contribution to an innovative approach to the poorly understood disabilities that are encountered by persons affected by chronic, evolutive pathologies, constructed at a time when the first evaluations of the impact of the February 11, 2005 law are underway, and in a context of ongoing major reforms of various sectors of the welfare system.

# PART I LIVING AND WORKING WITH HIV TODAY: DESPITE PROGRESS IN TREATMENT, DIFFICULTIES PERSIST

## I.1 HIV INFECTION IS STILL CONSIDERED A "SPECIAL" DISEASE

### I.1.2 STIGMATIZATION CONTINUES

In order to understand the impact of HIV on the socio-professional careers of affected persons, particularly their unmet needs for accompaniment and gaps in their welfare protection, we must examine the concrete mechanisms by which discovery of infection can throw individuals' social and professional lives into crisis. Their state of health is not the only parameter involved; the difficulties encountered in employment reflect a conjunction of personal factors and structural difficulties in coming to terms with society's very specific image of HIV infection. It remains an illness that is uniquely stigmatizing, and thus, whether they wish to reveal their illness or to conceal it, patients suffer severe social difficulties.

#### DIAGNOSIS: A MAJOR SHIFT IN PERSONAL HISTORY

Discovering that one is infected with HIV is no longer, in France, synonymous with a short or medium-term sentence of death. It remains, nonetheless, an event that dramatically disrupts a person's perspective on his or her future. It implies at the least living with significant doubts about one's health, and means that these persons must, for the remainder of their lives, deal with an evolving series of constraints linked to their state of health and their treatments, which will involve multiple consequences for their future social and professional lives as well as their emotional and sexual relationships.

However, the impact of the discovery of HIV infection appears to vary widely according to the time and the conditions in which it occurs. Important factors regarding the discovery of HIV infection include:

- Time: the person's age and stage of personal history;
- Context, in terms of emotional and family relationships;
- Natural history of the infection: the stage of illness at which HIV is discovered, from primo-infection to full-blown AIDS;
- History of the epidemic and its treatments at the time of diagnosis, particularly with respect to the shift created by the arrival of multi-therapies and medications that are simpler and easier to tolerate.

The age factor plays an important role in terms of social and professional integration, since it influences both the nature of the person's qualifications and his or her initial socio-professional situation. Intervening at a time when the person has not yet achieved academic and professional qualifications, diagnosis may compromise or defer them; or it may occur later, when the person is already in possession of professional qualifications and/or experience. Clearly an absence or shortage of qualifications and experience, particularly if accompanied by a precarious state of health, constitute a major obstacle to access or return to employment, and require support that focuses first and foremost on training for and re-integration into the job market.

Emotional context, in terms of family and relationships, affects the person's reaction to his or her diagnosis more generally, for example whether it is concealed or shared with close friends, family members, or within his or her social and professional sphere.

The third factor -- stage of infection at the time of its discovery -- determines the constraints of treatment and care, which vary widely according to the patient's state of health. An early diagnosis that does not require immediate treatment, and which may permit later initiation of multi-therapy under optimal conditions, offers far better chances for limiting the pathology's impact on professional life. Early diagnosis is a factor leading to successful treatment and consequently maintenance of good general health, high quality of life, and the absence or limitation of complications. The introduction of treatment can be thoroughly prepared and its eventual adverse effects anticipated. A late diagnosis, in a context of already damaged immunity or situations of clinical urgency created by opportunistic infections, multiplies the risk of sudden and significant damage to the patient's career.

The last factor, history of the epidemic, impacts the patient's perspectives on the future in that, since the arrival of effective treatments, the significance of diagnosis has altered. The historical dimension of the epidemic plays a special role for those who have been affected by the disease for the longest periods, and who thus initially experienced the illness as an inevitable death sentence in the short term. Multi-therapies have sharply altered this perspective, meaning that the question of employment may arise again after an interruption of several years. Such persons may have lived for years in poor health, with numerous disabilities, in very difficult financial situations and in conditions of social isolation; they may encounter great psychological difficulty in projecting themselves once more into the future, and their distance from the perspective of employment may be extreme. This type of experience of HIV, and the challenge of redefining a future for these persons that involves social and economic integration, require very specific forms of support and assistance.

The impact of HIV on patients' personal histories would be roughly similar to that of other long-term pathologies were it not for society's particular perception of the disease. HIV infection -- "AIDS" -- remains a widely stigmatized pathology. Thus the fragility of patients' employment status is not only impacted by their state of health, but also by the conditions in which they can, in a given social environment, come to terms with the implications of their illness and its constraints. To reveal their pathology or conceal it is a dilemma that confronts all patients affected by serious illness, but it is especially acute in the case of HIV infection.

## THE DILEMMA OF SECRECY

Studies show that HIV infection is more stigmatized than other chronic pathologies such as hypertension, diabetes or depression[1]. Data from the VESPA study indicate that 6% of persons employed at the time of interview felt that they had been victims of discrimination during their professional career because of their HIV seropositivity. This figure may not seem large, but it should be considered in the light of the fact that some 70% of HIV infected persons who remain employed keep their pathology secret from their employer and colleagues at work. This very high figure suggests that most employees associate revealing their illness with a risk of stigmatization or discrimination. The proportion of persons who have ceased to be employed since their diagnosis of HIV infection, and who feel they have suffered discrimination because of their serological status, is 13% -- significantly higher -- and this may imply that this type of discrimination played a role in their loss of employment.

Beyond these quantitative aspects, the qualitative implications of secrecy and the various forms of stigmatization and discrimination linked to HIV have been abundantly documented. Several different types of rejection of HIV-infected persons can be distinguished; although they involve different mechanisms, they are often concurrent.

*Fear of contamination*. Accounts of reactions of rejection in daily life, founded on irrational fear of imaginary risks of contamination (refusal to shake hands, use of toilets on another floor, fear of mosquito bites, disinfection of computer keyboards etc) are not only a feature of the epidemic's early years. Such reactions may still be observed today, in the most diverse workplaces -- including, sometimes, among certain occupational physicians -- and they demonstrate how important it is to continue even the most basic work of informing the public on HIV's modes of transmission.

*Moral disapproval*. HIV infection continues to suffer from an image as a shameful disease, which first arose from its principal modes of contamination and the initially most affected population groups, immediately perceived as "high risk" communities. Infection with HIV leads to questions and rumours about the origin of one's contamination, involving suspicion of practices that society prohibits or disapproves, and which are performed in secrecy, whether they involve drug addiction or sexual behaviour. In both of these respects the disease is perceived as the result of more or less deviant or irresponsible behaviour, suggesting either "divine retribution" or at least the idea of logical or even deserved consequences. Beyond the possible stigmatization of his or her pathology per se, when a person reveals his or her seropositivity in the work environment, this opens up speculation regarding his or her private life and supposed morals; the person will almost inevitably be forced to confront a series of prejudices that are sexist or homophobic, or involve addiction to narcotics. Even if hostile reactions are absent, the revelation implies permission to intrude into the private sphere, and it is difficult to set boundaries to this intrusion. Talking about HIV necessarily means talking about bodily practices, and always involves talking both too much and too little.

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[1] Roeloffs C, Sherbourne C, Unutzer J, Fink A, Tang L, Wells KB. Stigma and depression among primary care patients. *Gen Hosp Psychiatry*. 2003;25: 311–315. Quoted by Rosemary Dray-Spira, MD, PhD, Alice Gueguen, PhD, Jean-François Ravaud, MD, PhD, and France Lert, PhD. Socioeconomic Differences in the Impact of HIV Infection on Workforce Participation in France in the Era of Highly Active Antiretroviral Therapy. *Am. Jour. of Public Health*. 2007:97: 552-558.

*Unemployability*. Although infection with HIV is no longer a synonym for full-blown AIDS and a more or less rapid death sentence, the incertitude inherent in the evolutive nature of the disease constitutes a major obstacle to the employment of affected persons. According to the study "HIV and employment: the business perspective" (*VIH et emploi : le point de vue des entreprises)*, which was carried out under the aegis of AIDES, a non-profit association, in 2001, 100% of the employers interviewed declared they would not follow up a job interview with someone who stated that he or she was seropositive. Factors here include the role of irrational ideas about modes of contamination, which are the source of forms of discrimination specific to HIV and lead numerous employers to *a priori* exclude seropositive persons from various fields of work (professions involving food, contact with children, etc), but also a more general attitude of excluding employees who potentially present health risks. Employers anticipate a risk of lower performance and higher absenteeism from employees affected by a long-term illness. For the same reasons, people who have jobs and who reveal their seropositivity may then see slower progression of their career; their employers may not wish to take the risk of giving more responsibilities or key functions within the company to employees who may not be able to fulfil them. Numerous accounts describe employees being shut out from key jobs or fired from work on various pretexts due to this attitude.

As previously stated, fear of stigmatisation and the risk of exposure to various forms of discrimination if one's serological status is revealed lead many persons to conceal their infection. However, this strategy does carry risks. In a professional environment, concealment means that the employee must keep his or her medical appointments (consultations, exams, treatment) entirely separate from his or her work schedule, thus cutting into time for personal leisure or vacations and possibly undermining medical follow-up (forsaking consultations or medical exams for lack of time). It also implies that the employee renounces any possibility of modifying his or her job or work schedule for reasons of health, and that he or she limits as far as possible the frequency and duration of sick leave. This strategy may also compromise the quality of observance of treatment, if work schedules conflict with treatment schedules or if the workplace does not provide the necessary conditions of discretion. More generally, concealing HIV infection means that the person must maintain unchanged levels of performance despite the variable effects of the pathology or treatment on his or her physical and mental capabilities. The physical and psychological cost of these compensatory efforts and the management of this duality in daily life may be considerable, and may prove difficult to maintain in the long term.

### I.1.2 HIV IS STILL AN OBSTACLE FOR ACCESSING, MAINTAINING OR RETURNING TO EMPLOYMENT

At the end of 2007, the number of HIV-seropositive persons in France was estimated at between 113,000 and 141,000[2]. Because of the combined effect of therapeutic progress, which has meant a dramatic reduction in the number of deaths, and the uninterrupted progression of the epidemic, with roughly 6000 – 7000 new diagnoses of seropositivity every year, this population is constantly increasing. With an average age of 28 at the time of diagnosis of seropositivity[3], the vast majority of seropositive persons is of working age and is thus potentially affected by the problems of employment.

According to the Vespa study[4], within the population of persons living with HIV and of working age (under the age of 60), only 56.5% were actually employed in 2003. Those who did not have jobs were unemployed (18.1%) or inactive (25.4%). These overall figures conceal a number of important variations.

#### A POPULATION THAT FACES VARYING DIFFICULTIES WITH EMPLOYMENT

The population of people living with HIV is far from homogenous regarding the difficulties they face with respect to employment. Data from the Vespa study in 2003 show a gross employment rate of 53.9% among persons diagnosed with HIV before 1994, and 59.3% among those diagnosed after 1994. These levels vary widely, according to several factors that are usually associated with greater difficulty in the job market: the employment rate of seropositive women (44.6% among those diagnosed before 1994, 46.9% among those diagnosed since 1994) is lower than that for seropositive men (respectively 57.3% et 61.5% ); that of foreigners is lower than that of French citizens (49.5% and 47% *vs* 54.3% et 64.3%); that of persons with fewer years of study is lower than persons who have higher academic qualifications (48.5% and 53.4% *vs* 66.5 % and 72.7%).

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[2] Yeni P [dir.], *Recommandations du groupe d'experts, rapport 2008*, Paris, Flammarion Médecine-Sciences, Ministère de la santé, 2008.

[3] In 2007. *L'infection à VIH-sida en France*. Bulletin Epidémiologique Hebdomadaire, No. 45-46, December 1, 2008.

[4] All figures relating to employment rates quoted here and in following paragraphs, together with their proposed analysis, are based on an article by Dray-Spira et al., *Socioeconomic Differences in the Impact of HIV Infection on Workforce Participation in France in the Era of Highly Active Antiretroviral Therapy, op. cit.*.

The standardized employment rate (corrected to reflect socio-demographic composition comparable to that of the general population) is estimated at 49% for persons diagnosed before 1994 and 59.3% for persons diagnosed after 1994. The employment rate in the general population in 2003 was 65.3%.

Thus the Vespa study clarifies two factors: one linked to chronology of diagnosis, which is clearly affected by the evolution of available treatments, the other linked to social conditions prior to diagnosis.

The employment rate of HIV seropositive persons varies strongly according to the date of diagnosis: it is 25% lower than that observed in the general population for persons diagnosed before 1994, and only 9% lower for persons diagnosed after 1994. Quite logically, the effect of infection on the employment rate appears stronger in persons who developed the pathology before the arrival of effective tritherapies. However, the impact of infection remains significant even among persons who were able to benefit from effective treatments as soon as their infection was diagnosed.

This relative improvement of the overall employment rate conceals a number of growing disparities linked to pre-existing socio-demographic factors. Within the group of persons diagnosed before 1994, the employment rate of people with low levels of academic qualifications is 29% lower, and that of persons with higher levels of qualifications is 17% lower, than the employment rate of people with equivalent levels of qualification in the general population. This disparity appears far more significant in persons diagnosed after 1994. Among this group, the employment rate of persons with low levels of academic qualifications improves to only 14% less than the expected rate in the equivalent general population, but the disparity has grown with the group of persons with higher levels of academic qualification: their employment rate is similar to that observed in the general population. HIV infection thus operates as an amplifier of pre-existing social disparities even within a context of effective antiretroviral treatments, whose benefit is unevenly distributed in terms of the patient's employment situation.

Finally, the Vespa study demonstrates that a very high proportion of unemployed HIV infected persons – more than 64% - wishes to find work.[5]

## HIV REVEALS AND AMPLIFIES INITIALLY DISSIMILAR DIFFICULTIES

Epidemiological observations, which identify the population groups most exposed to risk, reveal the existence of factors of social and/or economic vulnerability that are strongly associated with the epidemic. The population groups that are most affected, in the sense that they concentrate the great majority of persons infected in France and/or register the highest prevalence -- male homosexuals; migrant heterosexuals, and particularly migrant women from sub-Saharan Africa; intravenous drug users; transsexuals; detainees in correctional facilities; and both male and female sex-workers -- are all, for different reasons and to varying degrees, marginalized groups within society. Clearly the obstacles that these groups encounter in society in general, and particularly in the job-market, differ profoundly, and clearly these are factors that may (but do not necessarily) contribute to a more fragile social position, one which the pathology may amplify into crisis. Sexual orientation may, for some individuals, be a source of discrimination in employment and/or social and family isolation, but many homosexuals are very well integrated into society and their professions. A migrant woman from sub-Saharan Africa will encounter different social situations depending on her immigration status (legal or illegal), her family situation, and her degree of integration or isolation from community networks.

Epidemiological observation describes a sociology of the HIV epidemic that has varied over the 25 years since the onset of the epidemic. The most obvious change has been the increase in heterosexual transmission, essentially affecting migrants, especially women. Thus among new diagnoses of seropositivity, more than half the heterosexual contaminations involve migrant persons from sub-Saharan Africa[6]. These populations tend to cumulate multiple administrative difficulties (irregular immigration status, difficulties in accessing health insurance and social welfare programs), economic difficulties (precarious and ill-paid work that is often part-time), and social and cultural difficulties (gender relationships, complex family situations, language barriers etc). These difficulties complicate and may dissuade such persons from access to treatment and care, and they make observance of treatment more burdensome, cutting down its chances of success[7]. The consequential damage to health may in turn have adverse effects on these patients' social and economic situations (loss of employment and/or income). In this sense, HIV today affects populations that are socially less well off and whose social and economic situation is more likely to be damaged by the pathology than in the first few years of the epidemic.

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[5] Dray-Spira R, Lert F, VESPA Study Group, *Living and working with HIV in France in 2003: results from the ANRS-EN12-VESPA Study*, AIDS 2007, 21 (suppl 1):S29-S36.

[6] InVS, *BEH* No.45-46, December 1, 2008.

[7] Several studies have clarifed these mechanisms and have established a clear link between precarious social conditions -- particularly problems with housing and resulting food security -- and difficulties with observance, which in turn are linked to lower success of treattment and higher morbidity and mortality in these groups.

The impact of HIV on the social and economic conditions of infected persons thus appears to vary widely according to the initial social context, leading today to a dual situation. Measured in terms of revenues, one group of middle-class persons maintains conditions close to those observed within the general population, while other groups appear far poorer.

## I.2 SOCIAL WELFARE BENEFITS ARE INSUFFICIENT AND POORLY ADAPTED TO NEEDS

The French social welfare system offers a number of measures to cover the different situations in which a person may, for health reasons, modify, reduce or temporarily or durably suspend his or her employment. These measures are of different types and their articulation is in many ways complex; a description of the main measures, presented in an annex to this document, gives a brief overview. The difficulties encountered by persons living with HIV are of course similar to those encountered by all beneficiaries of social welfare: the extreme complexity of the system and its modalities of access; difficulties in obtaining certain forms of assistance, involving delays that may be excessive, given the urgency of their situations; low levels of substitute revenues during periods of non-employment; difficulties in managing transitional periods between one measure and another, notably when returning to employment. However, the particular characteristics of the populations affected by HIV, relating either to their socio-demographic and economic conditions or their experience of the pathology and its treatments, tend to make these different problems more acute in their case.

### I.2.1 BENEFITS THAT ARE TOO COMPLEX AND TOO DIFFICULT FOR AFFECTED PERSONS TO ACCESS

The complexity of these benefits results from juxtaposition of different principles of access (access through rights acquired via financial contributions *vs* access by criteria of residence or resources) and the difference between basic national health insurance systems and optional supplemental systems (mandatory regimes *vs* optional regimes). To these differences, which are intrinsic to the national social insurance system, and which notably result in a multiplication of administrative actors, should be added the progressive "sedimentation" of various benefits, which are added to each other as the years go by, each with multiple and disparate eligibility criteria and involving various threshold effects and mechanisms for eviction.

#### THE LIMITS OF SOCIAL INSURANCE BASED ON RIGHTS ACQUIRED BY EMPLOYEES

The French national health insurance system was historically constructed, and remains founded on, a series of rights acquired through work, constituted by insurance funds for different forms of risk that are funded through specific taxes on employees and employers. The national health insurance fund partly covers medical costs, and gives access to substitute revenue, or "sick pay", during periods of medical leave, and to disability pensions in the case of durable or definitive inability to work. These health-insurance benefits extend to the legal beneficiaries of the insured person. The risk of loss of employment is covered by the unemployment insurance fund, which ensures a transitional income during the job-seeking period. The benefits of these various forms of insurance are thus conditional on the previous employment of the person concerned.

This system, which was conceived during a period when full employment and career stability were the general rule, appears today, in the current context of high unemployment, to be in crisis. Job insecurity, the fragmentation of careers into discrete periods of employment, and the multiplication of part-time work compromise, for numerous employees, access to these forms of assistance or to an adequate level of assistance.[8] The HIV epidemic, which affects many young people, tends to lead to multiple breakdowns in employment early in a person's professional career, and may interrupt their initial training and entry into the job-market. Moreover, some people living with HIV are characterized by significant risk factors for employment instability: this is the case for users or former users of narcotics, and also the case of migrants, who are particularly subject to precarious and fragmented forms of employment, often occurring within the 'black' economy, thus off the books.[9] Fragmentation of periods of employment that lead to contribution to social insurance funds, which is characteristic of many people's careers, may entail situations in which such persons may not have contributed sufficiently or for long enough to be able to claim relevant forms of assistance. Additionally, people who live with HIV may be less likely to receive coverage as the

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[8] Regarding sick pay and disability pensions, the National Consultative Council for Disabled Persons (CNCPH) notes, "The concept of half-pay (…) is not adapted to new forms of work organization, particularly precarious employment in which employees are paid the minimum wage and may find themselves, due to sickness or accident, living under the poverty level. The same is true regarding conditions for access to these substitute incomes, which despite the economic and social upheavals since 1945 (and particularly since the 1970s) remain defined for social conditions of full employment". (*Pour la garantie d'un revenu d'existence pour les personnes en situation de handicap*, CNCPH, 4 avril 2007)

[9] Notably the employment of women in the sectors of home help and cleaning.

legal beneficiaries of contributors to these funds, since they often live in social isolation, particularly if they are women, homosexual, and older than 50.[10]

### MASSIVE RECOURSE TO “SOCIAL MINIMA” BENEFITS

A number of benefits have progressively been established to compensate for the increasingly frequent cases of exclusion from the contributive system of social welfare. These benefits, known as the "social minima" (*minima sociaux)*, guarantee a baseline level of welfare protection, and minimum levels of income, for persons who have never qualified, or no longer qualify, for the general schemes of social welfare. Thus universal sickness coverage (CMU) permits coverage of medical costs, and various benefits may, depending on the individual situation, deliver minimal income: they include the adult disability benefit (AAH), specific solidarity benefit (ASS), and active solidarity income (RSA). These benefits are funded by taxation and their access is conditional both on criteria linked to their specific purposes and means testing.

Recourse to the "social minima" is very widespread among persons infected with HIV. Although the overall proportion of people receiving one of the ten "social minima" benefits is between 5% and 6% of the French population[11], more than one-quarter of HIV seropositive persons receive these benefits, and thus live on an income that is lower than the poverty level[12]. According to the Vespa study, in 2003, among persons living with HIV who had no income from employment, 28% were living on unemployment benefits, 35% on the adult disability benefit or other forms of disability pension, 10% were on sick pay and 9% received the minimal RMI benefit. 47% of these people had a monthly income lower than 760€[13].

Foreign citizens with irregular immigration status constitute a special case. They have no access to these various benefits. They may receive some coverage of medical costs via State medical aid benefit (AME), which is intended for foreigners who can document more than three months of residency in France and whose income is low.[14] Foreigners who cannot document presence in France for three months are only covered in situations of vital emergency. However, diagnosis of HIV infection can open the possibility of beginning procedures to regularise the person's administrative status, possibly involving welfare coverage. However, obtaining the right to live and work in France for medical reasons is currently a long and unpredictable procedure that often involves temporary authorisations which must be renewed after a few months (or at best one year), making access to the CMU benefit problematic, although it is theoretically possible.

### INSUFFICIENT ACCESS TO SUPPLEMENTAL COVERAGE

The weak economic position of many people living with HIV impacts their recourse to supplemental coverage. Subscription to good supplemental coverage would seem essential, to ensure optimal care and particularly to limit some of the miscellaneous costs that are not reimbursed by ordinary national insurance coverage. These costs, which have increased in recent years, may be estimated as at least 500€ per year[15], and may be accompanied by other forms of health spending that are not 100% reimbursed (dental care, gynaecological treatments, eye-care, health problems unrelated to HIV etc). Nonetheless, roughly one-third of people living with HIV do not benefit from supplemental coverage[16], compared to only 10% of the general population living in continental France.[17] Without

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[10] Emphasised in *Rapport d’experts 2008*, *op. cit.*, p. 358, which also notes that solitude is a factor associated with more rapid progression of the disease.

[11] On December 31, 2006, there were 3.5 million persons in France receiving *social minima* benefits (DREES, *Etudes et résultats*, n°680, février 2009), out of a total population of 64.6 million (INSEE).

[12] The poverty level as calculated by the INSEE corresponds to 60% of the median distribution of standards of living in the French population. For a person living alone it is currently 908€ a month.

[13] *Enquête ANRS-VESPA – premiers résultats*, *ANRS Actualité en santé publique*, November 2004.

[14] Income lower than a ceiling currently fixed at 606 € monthly. Unlike the CMU, the AME does not signify that its beneficiaries become fully insured and it does not cover all health costs. Notably, dental protheses and eye-glasses and access to medico-social institutions are not reimbursed.

[15] *Rapport d’expert 2008, op. cit.*, p. 362. These non-reimbursed miscellaneous charges essentially comprise charges for medical consultations exceeding statutory fees; the purchase of certain medications that are no longer reimbursed; various medical acts not registered as such by the official health-insurance "nomenclature"; daily deductible payments for hospital care; one-euro deductible payment per medical consultation; 18-euro deductibles for major acts in hospital; small copayments for medication (not affecting beneficiaries of the CMU).

[16] *Ibidem*

[17] In 2003, according to INSEE. See Marical F, de Saint Pol T, *La complémentaire santé : une généralisation qui n’efface pas les inégalités*, in : *INSEE Première*, No. 1142, June 2007. See also Raynaud D, *Les déterminants individuels des dépenses de santé : l’influence de la catégorie sociale et de l’assurance maladie complémentaire,* in : DREES, *Etudes et résultats*, No. 378, February 2005. This sizeable proportion may also be explained by the socio-demographic characteristics of persons affected by the HIV epidemic. The national average of 10% of persons not covered by supplemental medical insurance, recorded by INSEE, conceals very considerable variations according to age, standard of living and origin, among other factors. The rate of non-coverage rises to 14% among people aged 18-29, and is 21% among persons with the lowest standard of living. It is 46% among sub-Saharan Africans. The employment factor also plays an important role: all other factors being equal, people without

supplemental coverage, financial obstacles may be considerable for people with low incomes, and may lead some people to delay, or even forsake, some forms of treatment.[18]

The same type of inequality may be observed in supplemental insurance funds (*préyoances*) that offer additional coverage at various levels for sick leave (in addition to the basic per-diem sick pay) and in the eventual case of disability (in addition to the basic disability pension). This type of additional insurance, which may be linked to the supplemental medical benefit to which employees can subscribe or may be paid for collectively by the employer on behalf of all employees, is essential in order to limit the loss of income in case of long-term sick leave.[19]

### RECOURSE TO DISABILITY BENEFITS IS AMBIGUOUS

When a person must durably modify reduce or renounce professional activity, because of the impact of his or her state of health on the ability to work, access to welfare measures for compensation for or substitution of lost employment are conditioned by official recognition of disability. The various measures to assist disabled persons include previously cited specific substitute incomes including disability pensions and the adult disability benefit (AAH), alongside various measures aimed at compensating for the disability in daily life (support for care-givers, assistance with environmental modifications to the home and workplace etc) and particularly with access to employment; recognition of persons as disabled workers (RQTH), which may lead to assistance with professional retraining; access to support from agencies such as Cap Emploi; the obligation imposed on companies to employ disabled persons.

Access to these various measures, which is generally complex, is often delicate in the case of persons living with HIV, particularly because they often find it difficult to receive official recognition as disabled persons and to achieve an accurate official evaluation of their disability. During the initial years of the epidemic, recourse to disability measures usually focused on the AAH adult disability benefit, in a context when entry into the symptomatic phase of the disease meant there would be progressively more disabling damage to the patient's state of health until death. Although we should not underestimate the administrative difficulties encountered by patients at that time, particularly in terms of delays in obtaining benefits, the recognition of 80% disability became a general rule. This meant that the full AAH benefit was issued to persons who had lost their income from employment and had no hope of finding more work. The arrival of effective multi-therapies led to evolution of the course of the infection towards a more chronic pattern, and this radically altered perspectives. In terms of the AAH, fewer people living with HIV could obtain recognition of 80% disability, and disparities in practice by advisory physicians and commissions, in terms of their evaluation of disability levels, have become considerable, leading to inequalities depending on where the demand is registered and the persons in charge of evaluating the individual's situation. In particular, the issue of articulation of these benefits with the maintenance of or return to employment -- at first virtually nonexistent -- has become central. This problem extends far beyond the question of the AAH benefit, and involves the access of persons living with HIV to all measures to assist employment for disabled persons.

Recognition of the status of "disabled person" for persons affected by HIV remains, in practice, complex, within a system which, despite recent innovations stemming from the law on disability of February 11, 2005, continues to function mainly according to historically constructed views focused on a traditional concept of disability. Because of this focus, the welfare system has difficulty grasping the disabling, but often poorly visible and evolutive manifestations of HIV and other chronic pathologies. Moreover, even persons affected by such chronic pathologies often find it difficult to conceive of their problems in terms of a disability. Although it is clearly not desirable to impose the status of "disabled person" on all persons living with HIV, this conceptual obstacle may constitute a block to access to useful mechanisms for assistance.

### I.2.2 VERY LOW BASIC INCOMES MAINTAIN BENEFICIARIES IN AN ECONOMICALLY PRECARIOUS SITUATION

In the case of temporary or durable cessation of professional activity, lack of income rapidly becomes a major problem. Despite its ambitious objective of compensating for handicaps, the law on disability of February 11, 2005

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jobs are three times less likely to benefit from supplemental coverage. Finally, and paradoxically, the fact of benefiting from the ALD also appears to be associated with stronger risk of no supplementary health coverage. Thus 17% of persons not covered by supplemental health insurance are beneficiaries of 100% coverage from the basic national health insurance regime. All these factors are frequently combined in persons living with HIV.

[18] Measures do exist to assist persons of modest income to subscribe to supplemental insurance, but they have limited impact. The CMU-C offers free supplemental coverage to persons whose monthly income is no higher than 626.75 €. This ceiling, which is slightly lower than the AAH monthly payment (681.63 €), excludes those who benefit from the AAH. Given this threshold effect, a second measure permits people whose income lies between 626.75 € and 752.08 € to obtain financial assistance for the cost of subscription to supplementary insurance. Because of a lack of information about this measure, and the discouraging complexity of the conditions of access, only 600,000 people have requested it although 2 million are potentially concerned.

[19] Regarding the amount and ceilings of sick pay and disability pensions, and the question of loss of income that may result, see Annex.

largely ignored this essential dimension of basic incomes, in terms of their compensation for loss of income and loss of opportunity for the person who must reduce or renounce professional activity because of a disabling pathology. The multiple layers of complex measures previously described, which arise from multiple logical processes and institutions, only provide (in the absence of supplemental insurance) very low substitute incomes, and are often difficult to access. In practice they are unlikely to ensure a secure social and economic situation for the persons who must have recourse to them.

### SUBSTITUTE INCOMES ARE INADEQUATE AND INTERMITTENT

Medium- or long-term interruptions of employment, whether they are the direct result of health problems (sick leave, declaration of disability, loss of employment because of inability to modify or change jobs) or the result of the employer's action (dismissal, for whatever reason), lead to major risks of damage to the person's economic and social situation, and these risks are all the more difficult to confront when their initial situation, as is often the case, is already fragile. In a purely financial sense, reliance on the various forms of income benefit to which such persons may apply means, in the vast majority of cases, a drastic reduction in available income of roughly 50%, given the logic of "half-salary", or to their reduction to the very low level of one of the "social minima". The argument is sometimes made that the low level of basic income delivered by the "social minima" is compensated by more generous family benefits, or by intra-family solidarity, but this is rarely the case with HIV infection, since many patients have no children, live alone and have little family contact.

In addition to their low level, substitute incomes are often difficult to obtain. The complexity and delays of the application procedures often lead to gaps of several months before the benefit is rightfully delivered to the applicant. This is particularly the case for the administrative application of the AAH adult disability benefit, which in some departments of France can take more than 12 months[20]. Gaps of this kind in the continuity of benefits, and their low level, may lead patients to fall into a spiral of financial fragility, and may in particular compromise their housing situation. Thus they must confront, in addition to the difficulties of their illness and care, an accumulation of financial and administrative difficulties, reduction in standard of living, the need to find cheaper housing, psychological pressure and quite possibly feelings of loss of self-esteem and social position. These conditions and constraints can be a heavy burden on such persons' capacity to mobilize the necessary energy and time to return to employment, particularly if this involves looking for a new job and/or re-training or redeployment to a new sector of the job market. In this sense, the level of substitute incomes and their continuity not only impact the obvious issue of maintaining a decent standard of living, but also the question of patients' future prospects.

### BENEFITS ARE COMPARTMENTALIZED AND ARE TOO RISKY TO ABANDON

Many persons who suffer from chronic, evolutive pathologies may be able to pick up employment after more or less lengthy phases of sick leave, or may need to modify the volume of their employment. Measures that involve a substitute income should be able to take on the temporary characteristics of an emergency income that permits the patient to transit between phases of active employment, or to act as a complementary income accompanying reduced or modified employment. The rigidity and compartmentalization of most of these forms of benefit do not correspond to these needs. Beneficiaries are too often confronted with an "all or nothing" logic in which they must live either, solely, on their income from employment or, solely, on their social welfare benefits. Several disincentive factors may be at work. Firstly, employment may not necessarily bring additional income and may even in certain cases lead to a regression of the overall level of a person's income. Secondly, any increase (even a modest one) in a person's income may mean he or she too rapidly loses the right to benefit, which was obtained only after great difficulty. Finally, the fact of taking any form of employment may conflict with the criteria of non-employment on which certain forms of benefit are conditioned.

Although the system of disability pensions does, at least in theory, permit modifications in employment (so-called "1st and 2nd category" pensions are compatible with employment), the "social minima", paradoxically, are in practice very difficult to articulate with any kind of job. Reforms currently underway should tend to correct some of the mechanisms that discourage return to employment.

The RSA minimum income has now replaced the RMI, whose regulations permitted temporary combination of this benefit with income from employment. The RSA permits permanent combination, depending on the level of income from employment, and moreover diminishes threshold effects arising from the increased income. The effects of this recent reform in practice will require future study.

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[20] Audition

Several aspects of the AAH benefit that particularly discourage employment have recently been modified, including the mode of calculation of income[21], employment criteria[22], and the rules involving its combination with income-generating employment.[23] It is now possible to combine the AAH with income from employment, through a system of graduated deductions depending on the level of income. Thus until it reaches a certain level, income generated from employment is no longer entirely deducted from the size of benefit, and employment may thus lead to additional income, a measure that may encourage return to the job-market. However, the low level of the thresholds of deduction make the advantage a very small one, and the additional effects on access to other forms of benefit may make the ultimate financial result uncertain. Thus despite these improvement it remains very difficult for a person wishing to return to work to anticipate the real financial impact of his or her employment. The conditions for return to employment will only be significantly improved if reforms that promote the principle of cumulation of benefit and diminish threshold effects, comparable to those set up for the RSA, can be applied to the AAH. The authorities appear to be considering this type of reform of the AAH, but there has been no specific commitment to a time-table[24].

Despite some improvements, it remains complex and risky for persons benefiting from the "social minima" (and, to a lesser extent, from pensions) to return to work, given the fragility of their situation. Return to employment is often in itself a difficult challenge, involving the fear of being physically or mentally unable to perform in a new job, possible fear of confronting a new profession after redeployment to a new sector, and in certain cases fear of stigmatisation[25]. Unless a person can be sure of sufficient administrative and financial security, it may seem too risky to return to work, and the obstacles may appear insurmountable. Such persons become locked into unwanted inactivity and may find it increasingly difficult to return to employment as time goes on.

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[21] Regulations regarding accounting for income in the period prior to application, which have for a long time been poorly adapted to the evolutive nature of a patient's illness, now respond more adequately to situations of rapid deterioriation of health (regulation neutralizing the income of the preceding year).

[22] Until recently, a paradoxical regulation made it far more difficult for persons with a disability level between 50% and 79% to return to work. Although access to the full AAH is a right for persons whose disability exceeds 80%, if a patient's disability was lower than 80%, the AAH was only attributed on the double condition that they should be completely unable to exercise any professional activity due to disability, and that they should not have been employed for at least one year. Justified by the explanation that it sought to solve the difficulties encountered by disabled persons to find and maintain employment, this condition imposed in practice that people cease employment for at least a year before they could claim a substitute income. Thus, if they could not claim unemployment benefit, their only recourse during that period was the RMI or ASS, which provided income significantly lower than the AAH. This condition of non-employment, which affected the category of people most able to exercise a profession given their level of disability, discouraged them from finding employment and made it extremely risky to do so: if they found a job and then lost it relatively quickly, they once again had to wait for a year before being able to benefit from the AAH. New regulations have replaced the criteria of impossibility of exercising professional activity and non-employment for one year with the concept of "substantial and durable restriction in access to employment due to disability". In principle this concept is more flexible, but it is subject to interpretation, and thus its impact and real effects will need more study.

[23] Until 2008, in the case of income-generating employment, the income from employment was immediately subtracted from the level of benefit ("differential benefit"). Thus employment did not deliver a supplemental income unless it exceeded the level of benefit, and it could create new financial burdens, for example in terms of taxes, or lead to the loss of subsidiary allowances (for example, in the case of AAH, the Increased allowance for autonomy (MVA).) If employment generated income slightly higher than the level of benefit, it was highly likely that this would lead to a number of threshold effects eliminating access to various forms of benefit, or leading in turn to new burdens. This thus ultimately entailed financial disadvantages compared to the previous situation of non-employment.

[24] Hearing. See also the government's reponse to question No. 45561 published in the *journal Officiel* of May 26, 2009, p. 5166 : "(…) the government intends to conduct a policy of improving conditions for combining salary with benefits, so that access to employment no longer entails an immediate reduction in benefits. Thus benefits and salary may be completely cumulative for the first six months following access to employment; following this period, disabled persons will be durably permitted to combine their entire salary with a partial AAH benefit, calculated according to a single deduction based on their income from employment. Finally, a group of experts supervised by the General Inspectorate of Social Affairs is responsible for an inquiry into the employability of disabled persons, and their conclusions are scheduled for the summer of 2009. This concept will no longer distinguish between disabled persons according to their disability of more or less than 80%, but according to their real capacity or incapacity to work, so as to counsel them better. In addition, the Mediator of the Republic has reported that certain disabled person working in institutions and services of work assistance have had their salaries cut because of the calculation of their garanteed income together with the AAH. Apparently it is not the cumulation regulation as such that leads to income discrimination, but the discrepancy in the period retained for calculation of income. This is why, in the framework of the reform of the AAH announced during the National Conference on Disability on June 10 2008, the government has decided to update the level of AAH benefit every trimester, according to the income of the previous trimester. This new mode of calculation will permit more rapid adjustment of the level of AAH benefit to the evolution of the financial situation of its beneficiaries".

[25] According to the Vespa study, in 2003 64.5% of people living with HIV and without employment wished to return to work, and 58.2% had attempted to find work during the three months prior to interview. The reasons cited to explain the failure of these attempts included a lack of professional qualifications (44.8%), the lengthy period spent without employment (44.1%), anticipation of discrimination (30.9%) and work conditions incompatible with management of their illness (27.5%). Dray-Spira R, Lert F, VESPA Study Group. Living and working with HIV in France in 2003: results from the ANRS-EN12-VESPA Study. *Op. cit.*.

# PART II HIV INFECTION AS A PARADIGM FOR A NEW APPROACH TO DISABILITY

Given the difficult response by the social welfare system to HIV, the law on disability of February 11, 2005 provides the possibility of a fresh and innovative approach. Changing society's approach to disability is, however, a long-term process. The issues raised by HIV infection may contribute, within the spirit of the law, to the evolution of social images and practice.

## II.1 CONCEIVING HIV INFECTION, AND ALL CHRONIC AND EVOLUTIVE PATHOLOGIES, AS POTENTIALLY DISABLING

### II.1.1 DISABLED IN PRACTICE BUT NOT IN IMAGE

Spontaneously, HIV infection is perceived both by the persons affected and by society in general as falling into the category of illness -- "AIDS" -- and not as part of the category of disability, which carries images of physical and/or psychomotor handicap affecting the physical appearance or the body's social functioning in ways that are immediately visible. Perceiving HIV infection as a "handicap" clashes with ordinary perceptions, both of handicaps and of AIDS.

This attitude is perceptible among people affected by AIDS and among actors of the fight against AIDS, particularly non-governmental and non-profit associations. Although they may observe the objectively disabling character of the disease, they do not construct the identity of persons living with AIDS around the concept of these disabilities. Similarly, although social welfare protection of persons living with HIV does in fact build on measures historically conceived to benefit disabled persons, recourse to disability benefits seems, to date, to have taken place largely by default and almost by accident. Because the characteristics of their disabilities have not been positively thought through, these benefits currently fail to respond properly to their needs, particularly because they were initially conceived to respond to stable states of health and thus appear too rigid to respond to evolutive pathologies. The social agencies and administrations in charge of these benefits, and more generally the actors in the domain of disability, such as associations of disabled persons and the bodies in which they are represented, find it difficult to recognize HIV infection as a disability; it is difficult to take into account its atypical disabling aspects, which are evolutive and often poorly visible, and although there may be medically objective data concerning the pathology and physical deficiencies, it may be difficult to perceive their social repercussions. A significant fraction of the medical corps, including many occupational physicians, contribute to this image by focusing on treatment and biological results (which, today, are often favourable), to the detriment of an overall approach to the interaction between the person's state of health, treatments and life in society.

There is thus a clear discrepancy between the objective situation of patients and its image. HIV infection is, in practice, a disability, but it is not formulated as such, and its treatment by the social welfare system utilises the tools of disability without fully coming to terms with them.

#### POORLY VISIBLE DISABILITIES

In HIV infection there may be situations of major disability and dependence at an advanced stage of illness or because of related pathologies. However, progress in treatments has meant that these situations have become more rare. Most infected persons today are only affected by moderately disabling disorders that do not entail loss of autonomy. These disabilities are thus poorly visible, and their consequences are often insufficiently perceived and taken into account by the various actors. This is often true also for the effects of other chronic and evolutive pathologies.

The disabling effects of HIV infection and its treatment may include fatigue, constraints linked to medical examinations and care (medications, scheduling), various side-effects both physical and mental, and psychological repercussions. If they are not aware of these issues, the various actors will not be able to provide solutions that are adapted to the needs of HIV-infected people; indeed, their solutions may be counter-productive.

The disabling disorders encountered by affected persons may often be both diffuse and poorly visible, but they are likely to significantly alter their quality of life and their performance at work. They are partly due to the infection itself and partly due to its treatment, and they are of varying character and severity. Some are durable, and affect the physical condition and general mental outlook of patients in the long term; others may be episodic, leading to great variability in the physical and emotional state. In particular, even people who are relatively well in terms of virology may suffer from the following effects:

- greater likelihood of fatigue, sometimes characterised by sudden episodes of intense asthenia with no clear cause in persons who are otherwise in mostly good physical condition;
- disorders of concentration, mood, behaviour, sleep and libido, as well as depressive states;
- undesirable side-effects arising from medication such as nausea, digestive disorders, skin problems and neuropathic disorders;
- lipodystrophy following treatment with certain antiretrovirals, which may strongly affect physical appearance and negatively impact self-esteem;
- disorders that may be thought of as manifestations of premature aging, including loss of muscle mass, osteoporosis, rheumatic and neurocognitive disorders[26];
- increased frequency of more or less severe comorbidity, including lipid disorders, cardio-vascular pathologies, kidney failures, liver pathologies and various types of cancer.

All the disorders briefly outlined above have obvious repercussions on the social and professional life of patients, in ways that may be more or less acute depending on their combination and severity, ranging from simple social embarrassment to inability to work. Their impact is considerably augmented, and the patient's ability to manage them may be compromised, depending on his or her socio-economic situation (financial fragility and its impact on quality of housing, food and access to non-essential medical care) and emotional and social relationships (contact with family, social isolation, context of concealment of HIV infection from the partner and/or close family and friends). The arrival of one or several such disorders, which may occur after years of relatively serene management of the illness (for example when a simple change is made in treatment) may shake up the fragile equilibrium which the person has managed to establish and lead to major impact on his or her social and professional life.

Unless they are severe, many of these disorders may be relatively discreet and may (with the exception of certain severe forms of lipodystrophy) appear unrelated to HIV, since they can also be encountered in numerous other pathologies. If the person does not discuss them -- and even more so if he or she seeks to conceal them -- they may remain invisible to the people around him or her, particularly in a work environment, where other personnel may therefore neglect to take them into account in terms of the expectations they have regarding the person's performance. This absence of visible and manifest signs is both an opportunity (a normal social life may be preserved; the patient may continue to keep his or her pathology confidential) and a danger, since the early warning signs of breakdown may not be perceived.

This question of "invisible" disabilities is not unique to HIV; indeed, it is characteristic of most chronic or long-term pathologies. However, in the case of HIV it is reinforced by the question of concealment, which is not likely to be as pressing in most other pathologies, except to some degree in cancer (although the public's approach to this illness has altered in recent years). As for all disabling but poorly visible pathologies, it is difficult to conceive of them as disabilities, particularly since in the case of HIV the persons concerned may be understandably reluctant to signal their presence.

### II.1.2 DISABILITIES AND THE LAW OF FEBRUARY 11, 2005

The law on disability of February 11, 2005 did not merely reform the technical mechanisms providing disability benefits; it redefined the concept of disability. Although it may be appear imperfect and insufficiently thought-through in several respects, this law offers a new approach, potentially broadening the field of disability well beyond the usual image of a person who is visibly handicapped in terms of loss of physical or mental independence. By integrating the spectrum of disabling disorders, whatever their origin, which may lead to restricted activity and limit the person's participation in the life of society, the law opened an opportunity to rethink the consequences of chronic pathologies, such as HIV infection, in terms of disability.

#### THE SPIRIT OF THE LAW: CLEAR PROGRESS

According to the law of February 11, 2005, "A handicap is constituted by (...) any limitation of activity or restriction of participation in the life of society suffered by a person in his or her environment because of substantial, durable or definitive impairment to one or several physical, sensory, mental, cognitive or psychic functions; a polyhandicap;

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[26] Athough they have been poorly identified to date, neurocognitive disorders are an emergent problem because of the longer life expectancy of HIV-infected persons.

or a disabling health disorder."[27] Although this definition maintains the vocabulary of "handicap", it is unlike the traditional concept of handicap that has prevailed in France until now. The concept of handicap was implicitly centred on the person's characteristics, identifying the handicap with deficiencies and impairments. The new definition displaces this notion to a *situation* of handicap, and thus resituates disability within a person's relationship and interaction with a given environment. Disability is no longer an attribute inherent in the person, provoked by a physical lesion or illness; it is produced by a poorly adapted environment. Thus it is not so much the person who is disabled, but the society in which he or she operates that is disabling. This new definition of disability is closer to the UN's international definition of disability[28], which defines disability by the obstacles encountered to full participation in society, and consequentially aims actions in favour of disabled persons at the goal of insuring *accessibility* to all sectors of social life.

Thus the law marks a separation with the former model in which disability was present above all in the disabled person, and was apprehended in his medical and functional aspects through diagnosis and evaluation of deficiencies, and then acted upon in ways that were almost exclusively focused on the person (compensation, provision of devices to compensate for deficiencies). The task now is to rethink the environment's poor adaptation to the capacities of individuals, and to implicate society's responsibility. The person is no longer the problem; society is.

### THE LAW IN PRACTICE: MIXED RESULTS

This broader definition of disability that is the spirit of the new law, and its focus on the responsibility of all actors in society to compensate for disability, have been difficult to establish in practice given the inheritance of a previous model focused on detecting deficiencies and impairments preventing a person from achieving this or that type of task. In terms of evaluation of disability, the medical definition of impairment continues to be dominant.

The disability constituted by HIV infection, in terms of the repercussions on life in society that can be generated by the various disorders which it may entail, remains largely unknown, underestimated, or not fully evaluated by the different actors in this field. In terms of institutional actors specialized in disability (MDPH, national health insurance agencies, Agefiph and Fiphfp funds, and networks such as Sameth and Cap Emploi), the health actors involved in follow-up for these persons (personal physicians, occupational or workplace doctors), and also, more broadly, all other actors in the workplace, there continues to be significant room for improvement in terms of greater sensitivity to the issues and better tools for evaluation.

A major effort of advocacy and information needs to be effected so that images of disability can be changed at all these different levels, and in order to construct more appropriate tools for evaluation and guidelines for good practice.

## II.2 RETHINKING DISABILITY POLICIES TO INTEGRATE THE NEEDS OF PERSONS LIVING WITH HIV AND OTHER CHRONIC, EVOLUTIVE PATHOLOGIES

### II.2.1 PERCEPTIONS SHOULD EVOLVE, BRIDGING GAPS BETWEEN ACTORS IN HIV AND DISABILITY

Although the law lays down a conceptual framework that should encourage change in society's perception of disability, notably by integrating the problems of chronic, evolutive pathologies, this kind of change cannot be effected by law alone. The actors in this field need to enlarge their own image of disability in order to develop the law's potential. This requires work on such perceptions, both within the domain of HIV -- where, as in other communities organized around disabling pathologies, actors need to positively invest the question of disability -- and by actors working with disabilities, who must open up to the possibility of new forms of handicap not previously considered as such.

We should not underestimate the cultural gap that separates the traditional actors of disability from the actors of the fight against HIV. Disability has historically been structured around physical handicaps: firstly, wounded veterans from World War I (the *gueules cassées*), and subsequently handicaps occurring in the workplace. Only more recently, and essentially because of pressure from families organized into non-profit groups, has the question of care for congenital psychomotor disabilities become a focus, leading to the development of a sizeable medico-social sector in charge of caring for and eventually finding jobs for disabled children and young adults. The major parents'

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[27] *Code de l'action sociale et des familles*, book I, title I, chapter IV, Art. L. 114.

[28] Repeated in the *International Convention on the Rights of Disabled Persons*, Article 1, United Nations, August 25, 2006 : "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

associations have a dominant role in the management of this sector. The resulting approach to disability, which remains focused on caring for dependency and major handicaps, is characterized by the problems and family values of these groups. Notably, sexuality remains a taboo subject. Conversely, the fight against AIDS has been much more recent, and its non-profit groups have openly constituted themselves as pressure groups in the domain of sexuality (essentially homosexuality) and drug use, where their approach is highly political. Far from emanating from the families of persons affected by the illness, non-profit groups and non-governmental associations in the fight against AIDS are often constituted by persons who see them as an alternative to families who have failed to help or who are hostile to their sexuality, their lifestyle, and their illness. The activist cultures of these two types of groups are very different. Associations in the fight against AIDS appear to have a more militant approach; those in the field of disability have a more institutional image. Nonetheless, there is overlap, as with the "Neither Poor Nor Submissive" (*Ni pauvres, ni soumis)* movement, which saw a significant portion of actors in the field of disability working with associations against AIDS on common issues, while employing modes of action developed in the militant culture of HIV.

Associations in the fight against AIDS should develop their grasp of the concepts of disability, based notably on the notion promoted by the law of February 11, 2005. They should seek to help the institutional actors of disability policies and the traditional organizations of disabled persons to understand the essentially disabled situation of many persons living with HIV, and the need these persons have to see these disabilities understood and taken into account. In order for this to occur, such associations must obtain representation in the various bodies that have a role in disability policies (CNCPH, National Conference on Disability, MDPH network, Ministry of Social Affairs, Ministry of Labour). Given the structure of the field of non-profit actors working in HIV, they may be best advised to develop unified representation of their interests, just as they set up inter-association structures such as the TRT-5 group to unify their voices on issues regarding treatment. Although the specific characteristics of HIV should not be denied, these actors' audience could be strengthened if they could develop a common stance with associations of persons affected by other chronic pathologies, who encounter a number of similar problems. Initiatives such as the "Chronics Associated" collective (*Chroniques associés)* which groups AIDES, the FNAIR (National Federation for aid to persons with renal disease), JSC (Youth, Solidarity, Cancer), NAFSEP (New French Association for Multiple Sclerosis), Vaincre la Mucoviscidose (Cystic Fibrosis), and Keratos (ocular surface diseases) are pioneering this kind of common discourse.

### II.2.2 PUTTING INTO PRACTICE THE SPIRIT OF THE LAW OF FEBRUARY 11, 2005 INTO PRACTICE

Numerous institutional actors are involved in the care of disability, and the question of employment for disabled persons is even broader, involving all public-sector and private-sector employers and other actors in the labour market. Improving France's response to the questions raised by HIV will necessitate an effort to sensitize all these actors. This should benefit people affected by HIV but also, more widely, contribute to improving policies towards (and the situation of) people with chronic evolutive pathologies, both in terms of their job prospects and their benefits and welfare programs. Several practical recommendations may assist these various actors to formulate a better grasp of their problems and develop more relevant tools and guidelines for good practice.

#### SENSITIZING OPERATORS OF DISABILITY BENEFITS

The pluridisciplinary teams of MDPH agencies and the advisory physicians of national health-insurance agencies are the two main actors responsible for evaluating disability with the goal of allocating specific forms of rights and benefits to disabled persons. In order to better analyze and take into account the poorly visible disabling effects of HIV and other chronic pathologies and their repercussions on the social and professional lives of patients, their evaluations, and their criteria, tools and procedures, are clearly crucial questions.

Evaluation of disability by the pluridisciplinary teams of MDPH agencies aims to establish a *level* of disability*,* expressed as a percentage, whose value determines access to various benefits and rights (AAH, tax exonerations, RQTH status etc) that are bestowed by Commissions for the Rights and Autonomy of Persons (CDAPH). The examining physician of the MDPH determines the level of disability, or impairment, based on information formulated in a medical certificate drawn up by the personal physician (standardised form) and guided by a "Guide and scale for evaluation of disabilities and impairments of handicapped persons" (*Guide-barème pour l'évaluation des déficiences et incapacités des personnes handicapées*)[29] which is annexed to the Code of Social Action and Families (*Code de l'action sociale et des familles)*. The broad concept of a "level of disability" presented in the Guide and Scale includes not only the restrictive sense of capacity to work but all physical deficiencies and their consequences in a person's daily life. The Guide and Scale, at least in its most recent reformulation (dating from 2007[30]), is a useful

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[29] *Code de l'action sociale et des familles*, Annex 2-4, chapter IV.

[30] Cf. Decree No. 2007-1574 of November 6, 2007 modifying Annex 2-4 of the Code de l'action sociale et des familles, establishing the Guide and Scale for Evaluation.

evaluation tool which, when properly utilized, provides a good outline of the disabling disorders encountered during the evolution of HIV infection and its treatment. Difficulties in evaluation that have been observed in the field are thus rarely related to the tool itself, but to problems in reading and interpreting the patient's medical file: either the medical certificate is based on poor information, or the examining physician has failed to develop the sensitivity necessary for an adequate analysis of the diversity of the patient's disorders and their consequences on quality of life.

Regarding the first obstacle -- the quality of the medical certificate -- we observe that the information contained in the patient's file too often relates exclusively to biological and clinical examinations of the pathology itself (which are often very favourable, given the effective treatments available today) and that it underestimates, or fails to adequately and precisely describe, the disabling manifestations that the pathology entails, notably side-effects of treatments, psychological effects, fatigue etc. It is thus important that the medical certificate be drawn up by the patient's physician with the greatest care, bearing in mind all aspects of the illness that may affect quality of life. The personal physician should not approach this certificate as simply a tedious administrative formality than can be performed rapidly, outside of consultations; he or she must measure fully its crucial importance, and should aim to devote a significant amount of time to filling in the forms *during* consultation, accompanied by an in-depth dialogue with the patient that explores all possible dimensions of illness. The note of instruction to doctors that accompanies the forms for the medical certificate appears inadequate in this respect. It would be preferable that a document be drawn up, notably with the assistance of the associations concerned, to sensitize physicians and assist them to fill in the MDPH medical certificate.

The second obstacle -- the MDPH's team reading and analysis of the patient's file -- involves multiple difficulties. An effort must be made to sensitize MDPH pluridiscplinary teams, notably the evaluating physicians, to these areas. In this respect, the establishment of a coordinating physician in every MDPH, stabilisation of the teams and more generally, initiatives to boost the quality of available medical expertise (often inadequate in the former COTOREPs) are a vital first step. The CNSA, in its role as animator of the MDPH network, has the means to set up training programs and should support this dynamic. These qualitative efforts could be supplemented by establishing within each MDPH one referent person, who is trained in issues relating to disabling chronic pathologies, with the job of lending support to the evaluation of relevant files. Given the volume of applications received by the MDPH units, it may be difficult or impossible to guarantee individualized follow-up of every file by a single referent person in each unit, or to give every applicant the right to meet with the pluridisciplinary team. Nonetheless, the presence within every team of a referent person specialized in chronic pathologies who is better able to "translate" this type of application for the CDAPH, will certainly improve the quality of institutional responses. Additionally, in terms of the CDAPH themselves, it would be preferable that representatives of the associations of patients affected by chronic pathologies be integrated progressively into these bodies. Finally, in order to reduce the considerable disparities in practice observed among the different MDPH in France, deeper analysis will be needed to ensure more equal treatment. Decentralization to the level of the *département* or county, and the autonomous functioning of each MDPH with great differences in the organization of each of these structures, make it difficult to imagine any kind of strong national oversight. The role of the CNSA is limited to leadership of the network, and it is in no sense a central supervising body. In the absence of national leadership it may be possible to envisage a regional-based solution promoting more coherence among these agencies, in accordance with the logic of greater regionalization of the health system. Links between these agencies could be set up, to be defined with the future ARS. If such a coordinating structure were to be developed at a regional level, the Corevih could also provide useful contributions to better support for problems linked to infection with HIV.

Evaluation of impairment for the purposes of attributing disability pensions is performed by the Advisory Physicians of the national health insurance agencies, and the logic and criteria that they follow are somewhat different from those that prevail in the MDPH. The key concept for access to disability pensions is impairment or *invalidité*, by which term the health insurance agency means to measure the employee's theoretical degree of inability to work. *Invalidité* is defined by "an employee's inability to work or to earn income of at least two-thirds". In the absence of a formal reference scheme for levels of impairment, such as the *Guide and Scale*, this notion remains hazy. Notably, it is not clear whether the impairment is to result solely from physical deficiencies or whether, under a broader interpretation stemming perhaps from the concept of inability to earn, the concept is closer to the idea of employability, taking into account conditions of access to the job-market. A sizeable margin of interpretation is thus left to the Advisory Physician, particularly when the issue at question is not clear-cut physical impairment but an overall picture of poorly visible disorders. This too may lead to significant disparities in treatment. As with the physicians of the MDPH, it appears necessary to undertake strong efforts to sensitize the Advisory Physicians of national health-insurance agencies to the problems of HIV and chronic and disabling pathologies. In particular, efforts should be encouraged to emphasize a broader and more flexible use of the 1st category disability pension, which is compatible with return to work, and which could permit real modifications in professional activity of employees who are confronted with problems of fatigue or the impact of their treatment schedules on management of their work time. New training modules and informative publications should be developed by the national health insurance authorities (CNAM), and here too they could usefully include expertise from associations of persons living with chronic pathologies, particularly HIV.

Finally, agencies such as the Agefiph and Fiphfp funds, as well as the local operators Cap Emploi and Sameth, which are in charge of encouraging employment and professional integration for disabled people, should further develop their analysis of the specific characteristics of evolutive pathologies, particularly in terms of the variability of the disabilities they entail, which constitute a major challenge for maintenance in employment. Despite signs of some analysis of this type within the Agefiph, which notes the difficulties encountered by companies in managing the lack of certitude linked to variability of handicaps, this agency is currently, with the exception of a few rare and isolated local initiatives, engaged in no targeted action for this type of disability. Although the Agefiph prefers to take an approach that it terms "generalist," and thus refuses to embark on a logic of specific assistance to different kinds of pathology, it would be preferable that the principal agency financing the professional integration of disabled persons find ways to respond more adequately to the specific needs that are expressed by people living with HIV, and which are similar for people living with other chronic, evolutive pathologies.

The Agefiph also leads France's network of placement structures such as Cap Emploi, whose performance appear very disparate. The capacity of the Cap Emploi bodies to effectively assist persons living with chronic pathologies varies widely, depending essentially on the degree of integration of each structure within its local environment. The most effective Cap Emploi bodies are those that have managed to develop a significant network of links with the economic actors, different social services and local non-governmental organizations and non-profit groups. In this sense, non-governmental associations that undertake welfare care for persons with HIV (and the same logic holds for other pathologies, too) should develop as far as possible their contacts with local Cap Emploi bodies, in order to sensitize them better to the specific problems of their public. To further closer collaboration between these specialized associations and Cap Emploi, the social work performed by these associations should, moreover be recognized by and receive adequate support from partner agencies. The Agefiph's stated intention to work with the Cap Emploi network in 2009 in taking into account the variability of handicap should also contribute to improving the capacities for response of these bodies. Additionally, it may be useful to explore the possibility of setting up within each Cap Emploi a referent person for chronic pathologies, similar to the measure previously proposed for the MDPH.

In this regard, there appears to be inadequate support from the government and the Agefiph and Fiphfp specialized funds to bodies developing actions that promote professional integration for persons infected with HIV and who are at a distance from employment. In a number of cases, such integration programs have been developed by associations involved in the fight against AIDS. In other cases, more generalist bodies which include among their public persons infected with HIV have sought to develop actions adapted to their specific characteristics. These programs have been set up thanks essentially to support from Sidaction, whose Employment pole aims to develop projects that can respond to the new needs regarding return to or maintenance in employment that are expressed by seropositive persons, thanks to progress in treatments. The results of these experimental projects have demonstrated the virtue of constructing links and networks between bodies experienced in HIV and bodies experienced in professional integration. Establishing these programs on a more permanent footing, and extending them to all persons who could potentially benefit from them, now requires a real commitment from the government and bodies in charge of the professional integration of disabled persons.

## RETHINKING HEALTH AND WORK

Clearly the role of occupational and workplace physicians is, by definition, crucial to the management of efforts to integrate employees affected by HIV or other chronic and disabling pathologies, and to maintain them in the workplace. Their role is multiple: although the primary objective is to preserve the individual employee's health, occupational physicians have an essential mediation function between the employee and employer, and beyond their individual follow-up of individuals, they lead prevention actions on the collective level of the whole company or workplace. Ideally, the workplace physician is the interlocutor who can permit the employee affected with HIV to have the consequences of his pathology taken into account, without having to reveal it directly either to his employer or to his colleagues at work. Again ideally, the occupational physician should be the central pivot within the company for the work of informing and sensitize the group -- including the employer, top management and all personnel -- to the problems of employees confronting illness, and should encourage understanding, fight prejudice, calm irrational fears, affirm the principles of confidentiality, develop respect and solidarity, make measures to modify and adapt jobs intelligible to the group and enhance appreciation for the work capacities of persons working at modified jobs.

Occupational medicine is widely reported to be in crisis, and the essential role that it should play is far from adequately fulfilled in every case. The image of occupational medicine among employees suffers, firstly, from the ambiguous nature of the physician's links with employers, leading to doubts among employees about the physician's respect for medical secrecy. This crisis of trust leads many employees (particularly in the case of HIV) to refrain from informing the occupational physician about their pathology. In this way they deprive themselves of the possible benefits of modifications to their job description. These fears are reinforced by a second ambiguity arising from the physician's evaluation of aptitude to work, which may contribute, through various forms of drift, to a perception of occupational medicine as a selective mechanism at the service of the employer. The risk of being identified as unable to work becomes a guillotine which the employee seeks to avoid by concealing the difficulties he or she encounters in his job.

Proposed reforms of occupational medicine, which tend towards reinforcing the independence of health services in the workplace, and to clarification of their missions by defining the occupational physician as an interlocutor who counsels the employee in the management of his or her career and health, may in the future contribute to restoring this deficit in trust[31]. It will also be important to improve training for occupational physicians, including the problems of chronic illnesses and the disabilities they entail, both in terms of their initial training and refresher courses. Too often, faced with employees affected by chronic pathologies who find it difficult to continue full time work, an absence of anticipation and consideration of modifications to job descriptions leads to a physician declaring his or her inability to work and the breakdown of employment. Occupational physicians and other personnel involved alongside them in workplace health services must play a vital role as motors in defining and promoting innovative solutions within the workplace so that job descriptions, scheduling and rhythms can be adapted -- particularly through more flexible use of possibilities for therapeutic part-time work or 1st category disability pensions -- in order to respond better to the variability that characterises chronic pathologies and to create the conditions for durable maintenance in employment.

In addition to reform of the occupational medicine sector, it should be clear that the spirit of the law of February 11, 2005 calls for companies as a whole to adapt, in order to permit disabled persons to have full access to employment. Thanks to stronger regulations regarding the obligation to employ disabled people in companies having more than 20 employees, and also to a real change in attitudes among a growing number of employers about their social responsibility with respect to disability, significant progress has been made in recent years. This progress has been particularly clear in terms of adapting jobs to traditional handicaps -- motor and sensory deficiencies -- but it appears less significant with respect to poorly visible or invisible disabilities, for which adaptation focuses less on provision of material equipment, and more on flexibility in the rhythms of work and level of performance expected. The major difficulty remains the variability of the disability, which in the case of HIV and chronic pathologies is seen by the employer as generating uncertainty, and is more complex for small or very small companies to manage. Innovative solutions for such companies could involve their participation in groups of employers across a given economic zone; such groups may be better able to manage absences and replacements for employees affected by health uncertainties. Organizations of employers should be sensitizing their members to this issue and should encourage such measures, and the Agefiph should also develop forms of assistance and support that are adapted to this issue.

More widely, efforts to improve sensitivity to the questions of evolutive pathologies should be extended to all present in the workplace. The employer and human resources management, but also unions and representatives of employees, should work to inform all employees better and to fight prejudice and exclusion. Chronic pathologies -- which, according to Ministry of Health estimates, involve roughly 15 million people (or 20% of the French population) -- should no longer be invisible. HIV infection may affect only a small number of people, but it is one of the most difficult pathologies to reveal and to live with in the work environment. Thus it is a good indicator of the difficulties that we need to confront.

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[31] See on this point the recommendations of the Economic and Social Council: *L'avenir de la médecine du travail*, Avis et rapports du Conseil économique et social, Journal Officiel de la République Française, year 2008, No3, March 3, 2008.

# ANNEXE I DESCRIPTIVE OUTLINE OF THE MAIN WELFARE BENEFITS REGARDING SICKNESS, IMPAIRMENT AND DISABILITY

Description of the measures and benefits that may apply to people living with HIV during their illness is complex for several reasons. The nature and objectives of these benefits are diverse (care for the pathology, for its social and economic consequences). The welfare systems concerned, and their corresponding conditions for access, are very different: they may be insurance-type systems conditioned on sufficient contributions, or universal-type systems such as the "social minima" benefits that rely on national solidarity. The agencies involved in evaluating requests for aid and/or in financing these forms of benefit also vary widely, and may themselves operate in and depend on different levels of local, regional and national administration.

The presentation proposed below broadly distinguishes between three types of benefit, according to their objectives for their beneficiaries: coverage of costs of treatment, provision of substitute income, and measures to compensate for disability and encourage employment of disabled persons. For each of these three categories, the various benefits are listed according to the logic of the situation and history of the individual concerned. The figures cited in this presentation (value of the benefits and allowances, thresholds of resources etc.) are those in practice on September 1, 2009.

## I – COVERAGE OF HEALTH COSTS

Health costs -- medical visits, examinations, medications and hospitalisation -- are covered under the French welfare system by measures that combine obligatory health insurance with optional supplemental insurance (mutual insurance companies, private insurance companies, *prévoyance* insurance funds, CMU-C), which may provide partial or total reimbursement of health costs over and above that effected by the basic system of national health insurance.

### NATIONAL HEALTH INSURANCE AND THE ALD BENEFIT

The benefits of the basic system of national health insurance are acquired either due to salaried or similar work (contributions to the basic system), or, in the absence of professional activity, due to regular and legal residency in France (Universal Sickness Coverage, of CMU); or may be acquired by the legal beneficiaries of persons themselves insured. Infection with HIV is recognized as a "long-term condition" (ALD) which opens access to specific measures termed "100% coverage" to cover health costs directly related to HIV, and whose limits are fixed within a therapeutic protocol established by the personal physician and validated by the advisory physician of the national health insurance agency.

However, this "100% coverage" does not cover charges for medical consultations in excess of statutory fees; the purchase of certain medications that are no longer reimbursed; various medical acts not registered as such by the official health-insurance "nomenclature"; daily deductible payments for hospital care; one-euro deductible payments per medical consultation; 18-euro deductibles for major acts in hospital; or small co-payments for medication (not affecting beneficiaries of the CMU). These miscellaneous costs are estimated to amount to at least 500€ a year[1], and may be accompanied by other health costs not covered by the ALD benefit (dental care, some forms of gynaecological and optical treatment, and health problems other than HIV).

### SUPPLEMENTAL HEALTH COVERAGE

Subscription to supplemental coverage comprises reimbursement for part of the health costs not covered by government-sponsored health insurance. Agencies such as mutual insurance funds and private insurance agencies

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[1] Yeni P [dir.], *Recommandations du groupe d'experts, rapport 2008*, Paris, Flammarion Médecine-Sciences, Ministry of Health, 2008.

present a diverse range of options. Subscription to supplemental coverage may involve an individual contract, or a contract that is collective for all personnel in a workplace. As with the level of reimbursement they offer, the cost of supplemental coverage schemes is highly variable[2].

Two measures have been set up to assist people with low incomes to access supplemental coverage, depending on their level of income. The first, **CMU-C**, provides free supplemental coverage for persons whose monthly income does not exceed 626.75€[3]. It should be noted that this threshold is very slightly lower than the monthly adult disability benefit, AAH, and thus beneficiaries of the AAH cannot access the CMU-C. The second measure, Assistance to Acquisition of Supplemental Coverage **(ACS), is intended for persons whose monthly income lies between** 626.75€ and 752.08€[4]. It consists of financial assistance towards the cost of subscription to supplemental coverage, and ranges from 100€ to 500€, depending on age.

### FOREIGN CITIZENS WITH IRREGULAR IMMIGRATION STATUS

Foreigners whose immigration status is irregular, and who are not admitted to the general system of health insurance by virtue of salaried employment or as legal beneficiaries, cannot access the CMU, which requires foreigners to be legal immigrants in France. For such persons, the State Medical Aid **benefit (AME) permits access to free health care, on condition that beneficiaries can document presence in France for longer than three months, and a monthly income lower than** 606€. The AME does not give beneficiaries the status of insured parties. It covers hospital health costs and doctors' consultations, with the exception of dental prostheses, eye-glasses and the cost of residence in medico-social institutions.

For foreigners who are not eligible for the AME, particularly those who cannot document the necessary three months of residence, only vitally urgent care can be covered, in a hospital environment.

Diagnosis with a severe pathology, and notably HIV infection, may permit foreigners with irregular immigration status to launch an application for legal residency (authorization of residence for purposes of medical treatment), which means in principle that such a person will obtain welfare coverage (CMU).

The **PASS benefit (Permanent Access to Health Care)** may also permit access to care for persons who do not have welfare coverage, by assisting them in the administrative procedures required to receive benefits.

## II – BASIC SUBSTITUTE INCOME, DETERMINED BY SITUATION REGARDING EMPLOYMENT

People who exercise salaried or similar employment, and who fulfill various conditions regarding the duration of that activity[5], benefit, in the framework of the national health insurance system, from substitute incomes when their state of health forces them to interrupt or limit their professional activity. This income may take the form of a *per-diem* sick pay, or that of a disability pension, depending on whether the restriction of employment imposed by sickness is temporary or durable. Unlike benefits in kind (such as coverage of health costs), these cash benefits issued by the social insurance system are delivered only to the insured party, by virtue of his or her employment, and thus do not cover legal beneficiaries or people benefiting from the CMU. In case of loss of employment, the rights to sick pay or pension acquired by virtue of employment are maintained for the 12 months following termination of the employment contract, and, if there is unemployment benefit, during the entire period in which that benefit is delivered[6], and for 12 months following its termination.

Persons with no professional activity, or whose employment is or was insufficient or ended at a period too distant in time to permit them to benefit from these forms of assistance, may be able to access the "social minima" benefits,

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[2] For a description of supplemental insurance contracts that analyses the coverage they guarantee, see *Typologie des contrats les plus souscrits auprès des complémentaires santé en 2006,* Drees, *Etudes et Résultats*, N° 663, octobre 2006.

[3] In the case of a person living alone. Other income threshholds are employed, depending on the composition of a given household. See www.securite-sociale.fr/chiffres/baremes/montant_aide_cplmtaire.htm

[4] Cf. preceding note.

[5] A worker in the private sector must have contributed to the system for at least 12 months, based on a salary that is equivalent to the SMIC minimum wage or above, in order to obtain sick leave for longer than 6 months; or must have worked at least 800 hours over the preceding 12 months, including at least 200 hours in the first three months.

[6] Including payment of the Specific solidarity allowance (ASS).

either benefits that are open to all (RSA) or those linked to recognition of disability (the AAH and associated allowances).

### SUSPENDING EMPLOYMENT TO PERMIT TREATMENT: SICK LEAVE AND SICK PAY FOR LONG-TERM CONDITIONS

In the short and medium term, sick leave gives workers the right to receive per-diem sick pay as a substitute for their salary. This per-diem sick pay (*Indemnités Journalières,* or IJ) is paid to the patient as of the 4th day of sick leave and for a cumulative duration of a maximum of 3 years[7]. Depending on the number of dependents and the duration of the person's sick leave, this per-diem is calculated at between half and two-thirds of the average salary received in the 90 days preceding sick leave, up to a maximum that is based on the ceiling rate of the health-insurance system[8]. Sick pay within the context of a long-term condition (ALD) is not considered taxable income. The following table outlines in a simplified manner the form of calculations involved, and the current income ceilings:

| | Sick leave of up to 3 months | Sick leave greater than 3 months |
|---|---|---|
| **Fewer than 3 dependant children** | sick pay = 50% of salary<br>→ up to a limit of 47.65€ /day (i.e. 1429.50€ / month) | Increase of 1 % or other more favourable regulations may apply |
| **3 or more dependant children** | Up to 31 days, sick pay = 50% of salary<br>After 31 days, sick pay = 66.66% of salary<br>→ up to a limit of 63.53€ /day (i.e. 1905.90€ / month) | |

The fall in income that results from the per-diem sick pay system is considerable. In general, a full-time employee with fewer than 3 children, who is paid the SMIC minimum wage (1337.70€ per month gross, in other words 1050.63€ per month net, before income taxes), will see his or her income cut to 670€ net per month. A more highly paid employee, whose gross monthly salary is higher than 2859€, receives sick pay only up to the maximum ceiling, i.e. 1429.50€ per month. Certain supplemental health coverage or insurance funds offer compensation for all or part of this loss of revenue during periods of sick leave.

### LONG-TERM INABILITY TO WORK: DISABILITY PENSIONS

In the long term, once the maximum three years of sick pay have expired, or before this date if the person's health situation does not suggest the possibility of future return to the job market, the employee may benefit from a disability pension. If older than 60, this disability pension becomes an old-age pension. Depending on the evaluation of the Advisory Physician of the national health insurance agency, the disability pension is allocated on the basis of "inability to work of at least two-thirds". It is accompanied by a classification into three categories.

The 1st category pension amounts to 30% of the "baseline average annual salary" (SAMB)[9], up to a maximum ceiling defined by the health-insurance system. In 2009 this maximum was 857.70€ per month. This category of pension applies to employees identified as capable of income-generating employment. It may thus be combined with a salary, up to the reference salary previously earned.

The 2nd category pension amounts to 50% of the SAMB, and its current ceiling is 1429.50€ per month. This applies to employees unable to exercise income-generating professional activity, or who, although theoretically unable to do so, may be able to hold down a job if it does not endanger their health. In this case, the same rules in application for the 1st category pension apply, in terms of combining the benefit with any form of salaried income.

Finally, the 3rd category pension applies to employees who are absolutely incapable of exercising any professional activity, and who must have recourse to a third person in order to effect ordinary acts of daily life. It amounts to

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[7] Only in the case of a pathology recognized by the health insurance agency as a long-term condition.

[8] Fixed by regulations that are revisited every year. For 2009, the ceiling is 34,308 € per year, or 2859 € per month. (*Decree No. 2008-1394 of December 19 2008 fixing the ceiling of the Sécurité Sociale for 2009*)

[9] The SAMB is an average of salaries in the ten years of highest income, modified by a coefficient updating their value in order to express them on a constant-year basis.

50% of the SAMB, and may be increased by a "third-person allowance" of 1029.10€ per month[10]. Including this allowance, the ceiling of this pension is thus 2458.60€ per month (1429.50€ + 1029.10€).

These disability pensions may not amount to less than 262.97€ per month (all three categories of pension).[11] Given basic needs, in the absence of any other income, or if the total income (including the pension) is lower than various thresholds[12], an additional allowance may be allocated as part of the Special Disability Fund **(FSI), in order to ensure a basic income of roughly** 640€ per month to people receiving disability pensions. The Special Disability Allowance **(ASI)** is issued within income limits, and may not exceed 4520.24€ per year for a person living alone (376.69€/month), or 7459.07€ per year for a couple (621.59€/mois). A person who receives a disability pension amounting to less than the Adult disability benefit (AAH), and who is eligible to receive the AAH, may combine his or her pension with a fraction of the AAH up to the value of the full AAH benefit, which is currently 681.63€.

As with sick pay, some forms of supplemental and insurance may provide financial supplementation to the disability pension.

### FOLLOWING LOSS OF EMPLOYMENT, BENEFITS ARE TEMPORARILY RETAINED

Employees who lose their job and professional activity may nonetheless be able to claim sick pay or a disability pension within a certain time frame, so long as they had acquired the right to do so prior to interruption of their contract of employment, and within the conditions that prevailed on their last day of work. Thus, during the period of unemployment benefit (Specific Retraining Allowance (ASR); Allowance to assist return to employment (ARE); Specific Solidarity Allowance (ASS)[13]), and for the twelve months following the termination of those benefits, the employee who is declared to be on sick leave substitutes his or her unemployment benefit with per-diem sick pay, calculated as a function of average salary for the 90 days preceding the end of his or her contract of employment. The period of unemployment benefit is then prolonged for the appropriate number of days. If an unemployed person is no longer receiving benefits, so long as he or she contributed sufficiently prior to termination of the employment contract, these regulations remain in force for twelve months following the end of the contract. This is also true for the person's right to claim a disability pension, and, similarly, the conditions for eligibility are based on the person's situation on the last day of his or her contract of employment.

### THE "SOCIAL MINIMA": A LAST RECOURSE

The "social minima" benefits, whether they are linked to disability (Adult disability benefit (AAH) and related allowances) or open to all (RSA), constitute a last recourse for persons who have not acquired sufficient access to other benefits by virtue of previous employment.

#### ADULT DISABILITY BENEFIT (AAH)

The maximum monthly **AAH benefit**, 681.63€, may be allocated to persons residing permanently and legally in France, whose income is low and who have a stipulated, officially recognized degree of disability. The size of the allowance depends on the person's income within a certain threshold, taking into account all revenues of his or her household[14] during the calendar year n-2[15]. The income ceiling for a person living alone is 8003.52€ (an average monthly income equivalent to the maximum AAH benefit) and for a couple it is 16,007.04€, to which may be added

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[10] Increase from the "third person allowance" is suspended in the case of hospitalisation.

[11] Not counting the "third person allowance" in the case of 3rd category pensions. Including that allowance, the minimum benefit is 262.97 € + 1029.10 € = 1292.07 €)

[12] Income, including the pension, lower than 7859.08 € / year for a person living alone (654.92 € / month), or 13,765.73 € / year for a couple (1147.14 € / month)

[13] One of the "social minimums", the Specific Solidarity Allowance (ASS) is given to persons seeking activity once the ARE is exhausted, if they document five years of work in the ten years preceding termination of their employment contract. It is conditional on income (1047.20 € for a person living alone and 1645.60 € for a couple, calculated from the 12 months preceding the last payment of the ARE). In 2009, the ASS maximum benefit was 448.80 € / month, although only a portion of that maximum may be allocated, depending on the person's income within the maximum threshold. The ASS is allocated for 6 months (renewable) and is conditional on actively seeking employment.

[14] Calculated on the basis of net revenue of the household as estimated by the income tax authorities, increased or decreased by specific revenues, charges, and threshold calculations. In particular, family allowance benefits; income from future contracts or contracts for professional integration associated with the RSA (CI-RMA) that have been signed by the disabled person by virtue of his qualification as a beneficiary of the AAH; and the salary paid to a family care-taker (if this person is the partner of the beneficiary) are not included.

[15] For example, for requests to receive the AAH made during the year 2009, the calculation is based on income from the calendar year 2007. However, when a beneficiary has ceased all professional employment and has no substitute income, the income from professional activity and unemployment benefits received in the reference year are not included in the calculation. (Rule termed "neutralisation of income"). This measure applies from the first day of the calendar month following the change in situation, to the last calendar month preceding the month in which the individual returns to employment.

the sum of 4001.76€ per dependent child. The AAH is allocated to all qualifying persons whose level of disabilities exceeds 80%. For those whose level of disability is considered to be between 50% and 79%, the AAH is now allocated on condition that the person encounter "substantial and durable restrictions in access to employment due to disability", a criteria whose mode of evaluation in practice will be detailed in an upcoming decree[16].

It is possible to combine the AAH with income from employment, using a decreasing series of thresholds applied to this income. Four threshold levels exclude, respectively, 40% of annual income lower than 300 times the minimum hourly wage[17] (thus 8.27 x 300 = 2481€); 30% of income that is between 300 and 700 times the minimum hourly wage (thus between entre 2481€ and 5789€); 20% of income between 700 and 1100 times the minimum hourly wage (thus between 5789€ and 9097€); and 10% of income between 1100 and 1500 times the minimum hourly wage (thus between 9097€ and 12405€).

From the age of 60, the AAH is no longer applied if the beneficiary's disability level is between 50% and 79%, and the beneficiary is redirected to retirement benefits for the disabled or the Solidarity Allowance for Elderly Persons (ASPA). In the case of disability exceeding 80%, a fraction of the AAH benefit may be allocated, if the retirement pension is lower than the "old-age minimum" (*minimum vieillesse).*

Requests to receive the AAH benefit must be addressed to the services of Departmental Agencies for the Disabled (MDPH). Decisions regarding attribution of the AAH are made by the Commission for the Rights and Autonomy of Disabled Persons (CDAPH) within each MDPH. The resources of beneficiaries and effective payment of the benefit are checked by the Family Allowance Agency (CAF).

### ALLOWANCES RELATED TO THE AAH

- The Guaranteed Income for Disabled Persons **(GRPH)** is made up of the AAH and an additional allowance of 164.64€, for a total 846.27€. It concerns disabled persons who have been recognized as unable to work but who wish to preserve their independence, and is accessible to beneficiaries of the full AAH benefit whose disability level is 80% or above, and whose capacity to work is evaluated at lower than 5%. The beneficiary must have received no income from professional employment during the year preceding the request, and must live in a accommodation that qualifies as "independent", according to precise criteria.

- The Increased Allowance for Autonomy **(MVA)** is another AAH-related allowance, amounting to 104.77€, and may be applied, on certain conditions, to beneficiaries of the full AAH benefit whose level of disability is 80% or more, and who are able to work but do not have employment. Beneficiaries who wish to apply for this allowance must live in accommodation qualifying as "independent" and receive housing aid.

- The GRPH and MVA allowances cannot be cumulative.

### THE ACTIVE SOLIDARITY INCOME (RSA)

For persons not eligible to receive the AAH benefit, the RSA (which replaced the former RMI on June 1, 2009) may constitute a minimal income source. The principle behind the RSA is that it guarantees its beneficiaries a minimum income, whatever their employment situation. It may be allocated to unemployed persons who have no income, or to persons who have employment but whose pay is low. It is accessible to persons over 25 (with the exception of students), who hold French nationality or who (if foreign citizens) are resident in France and fulfill certain administrative conditions. The amount of the RSA benefit depends on the income of the person, his or her family situation and the value of his or her personal property, and is calculated based on the combined income of the household (62%) and a fixed sum that varies according to the composition of the household and the age of the people within it. Thus the beneficiary may combine up to 62% of his or her salary with this allowance, on condition that income from work not exceed 1.04 times the minimum wage (SMIC). For a person living alone and without income, the RSA is the same as the former RMI, i.e. 447.91€ per month.

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[16] This measure replaces the previous double condition of being unable to exercise professional activity because of disability, and 12 months without any employment prior to the request to receive benefit.

[17] Value on January 1 of the year n-2, thus, for a calculation in 2009, on January 1, 2007. The hourly minimum wage in effect at that date was 8.27 €.

# III - MEASURES TO COMPENSATE DISABILITY AND ENCOURAGE THE EMPLOYMENT OF DISABLED PERSONS

### SUPPORT TO COMPENSATE FOR DISABILITY

The February 11, 2005 law on disability lays down the principle of compensation for disability, in institutions or at home. Depending on the disabled person's project for the future, a personalized plan compensating for the disability is drawn up, which aims to guarantee the person the greatest possible personal independence. The measure to support and compensate for disability (***prestation de compensation)*** covers all needs for assistance (technical, human and/or animal), as well as modifications to the person's housing or vehicle that may be necessary to achieving the personalized plan.

The plan compensating for disability is drawn up by the pluridisciplinary MDPH team, after interviews regarding the person's plans for the future. Decisions to attribute compensatory support are taken by the CDAPH, and may include five major kinds of assistance:

- Human assistance: compensation or salary for family carers, professional care-givers, or other third persons ;
- Technical assistance: purchase of necessary equipment and material such as prostheses, wheelchairs, computers with appropriate interfaces etc;
- Modifications to housing or vehicles, and compensation for excess transport charges arising from the disability;
- Animal assistance (guide-dogs for the blind, other assistance dogs);
- Specific and exceptional assistance, when needs are not covered by other types of assistance.

### MEASURES TO ENCOURAGE THE EMPLOYMENT OF THE DISABLED

#### EMPLOYERS: THEIR OBLIGATIONS, AND ASSISTANCE AVAILABLE TO THEM

In order to promote the employment of disabled persons in normal workplace environments, disabled persons must constitute at least 6% of the workforce in private-sector companies with more than 20 employees. Companies that do not fulfill this obligation must contribute to the National Association for Management of the Fund for Professional Integration of Disabled Persons (**Agefiph**). The law of February 11, 2005 reinforced this contribution, notably by tripling its size for companies who had made no efforts to fulfill their obligation after three years. The obligation to employ disabled persons was extended to the public sector, and a Fund for the Integration of Disabled Persons in the Public Sector (**Fiphfp**) was set up, with objectives similar to the private-sector Agefiph.

The obligation to employ disabled persons is accompanied by measures to assist employers, either by compensating for expenses necessary to permit employment of such persons, or by giving technical and logistical help in adapting the work environment.

Agefiph and Fiphfp agencies offer employers the following subsidies and assistance:

- **Assistance with recruitment: subsidies for integration of the disabled, depending on the type of contract or apprenticeship** (*prime à l'insertion, prime contrat durable, prime initiative emploi, aide à l'apprentissage* and *contrat de professionnalisation),* assistance with training and financing a tutor for incoming disabled employees *(aide au tutorat)*, and subsidies for modifications to the workplace.
- **Assistance with maintaining disabled employees in the workplace: grants (***aide au maintien dans l'emploi)*, and support for modifications to the workplace (*aide à l'adaptation du poste de travail)* or to cover modifications to the work schedule with maintenance of full salary (*aide à l'amenagement du temps de travail).*
- **Assistance to encourage the integration and professional evolution of disabled employees, including various subsidies for training programs for disabled employees to improve their integration and reinforce their skills**.

Additionally, companies can turn to various bodies for support, such as:

- Agencies to promote the maintenance of employment for disabled workers **(Sameth)**. Sameth agencies, which are situated in each of the 100 French *départments* or counties, offer free advice and assistance to private and public-sector employers to encourage the maintenance in employment of employees who, due to the advent or aggravation of disability, find it difficult to maintain their position in the workplace. They inform employers about the various ways to seek specific forms of benefit, such as those listed above, and assist them with the necessary administrative formalities. A specific technical pole assists with seeking and setting up technical, human or organizational solutions as well as with the mobilisation of financial assistance.

- **Cap Emploi** agencies are specific placement organizations for unemployed disabled workers, and are present in every département. Cap Emploi counsellors give disabled job-seekers help and advice regarding their recruitment and integration (analysis of the current local job market, information regarding ways to compensate for handicap and modify the workplace, search for candidates, mobilisation of existing benefits, help with preparing job applications, follow-up for persons newly recruited etc).
- Life At Work services, proposed by the Agefiph, are targeted at private-sector employers, and aim to improve the future career prospects of disabled workers, by providing expert diagnosis (analysis of the specific company, the situations encountered by the disabled employee, and how best to match the specific job description with the particular disability involved, the company's future plans and the worker's desired career path) and a plan of action (plans for training or tutoring, modifications to the workplace and/or sensitisation of other employees), as well as follow-up.

### DISABLED WORKER STATUS

A disabled person can request the MDPH to officially recognize his or her status as a disabled worker (Recognition of Status as a Disabled Worker, **(RQTH))** in order to access various benefits encouraging his or her professional integration. The RQTH is issued by the CDAPH. This recognition of status as a disabled worker is entirely independent of the attribution of an Adult disability benefit (AAH), a disabled identity card, or to compensatory support. [18]

RQTH status means that the disabled employee can benefit from the obligation to employ disabled persons outlined above. It also means that, if necessary, the disabled worker can be directed to an institution or agency for assistance through employment (ESAT), or to a centre for professional retraining.

The RQTH also opens the door to various measures to help with employment and training that are provided by the Agefiph and Fiphfp, and particularly by Cap Emploi. Beneficiaries can access jobs in the public sector through examinations (which may be modified) or by specific contractual recruitment. Finally, in the case of termination of employment, the duration of the notice period for termination is doubled, up to a maximum of three months.

The Agefiph offers disabled workers a number of services and forms of assistance:

- **Project assistance services, which are jointly run by the** MDPH and Agefiph, are open to any person who requests RQTH status, and aim to provide disabled persons with help in defining their desired future career path.
- Assistance with evaluations of skills and professional orientation is given to disabled persons seeking training or employment, or who are currently employed and seeking to forward their career prospects. Employers may also request this assistance.
- **Assistance in training job-seekers helps disabled persons seeking employment to acquire skills and knowledge necessary to obtaining jobs**. It comprises financing (or co-financing, together with national or local government authorities or the government-run Pôle Emploi employment agency) the educational costs of training programs essential to furthering access to employment. It may include financing training persons to use new technologies, or help to obtain a driver's licence, or (in partnership with companies), subsidies for programs for apprenticeship and recruitment (***aides à l'apprentissage, aides au contrat de professionnalisation)***.
- **Assistance with maintenance in employment is designed to help employers, but may also be given to disabled persons who are freelance or independent workers. These persons may also access the services of the Sameth.**
- **Assistance with mobility: this kind of support can vary widely, but its goal is to compensate for problems involving mobility that are obstacles to employment. It may comprise subsidising the cost of suitable transport to and from the workplace, financing a driver's licence, or subsidies for purchasing and/or modifying a vehicle.**

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[18] However, even in the absence of RQTH status, beneficiaries of the AAH, the disabled identity card, or support to compensate for disability benefit automatically from the rights and advantages bestowed by the RQTH.

- **Human and technical assistance is aimed at financing measures to compensate for disability (care-givers, technical equipment etc) that are necessary to maintain, develop or access professional activity.**
- **Assistance with self-employment and setting up a business is targeted to disabled persons seeking employment, and includes a number of measures to assist with creating a new company or taking over an existing business (subsidies, management training, individual follow-up, modification of conditions to access credit and insurance**).

Access to the Cap Emploi placement network allows a disabled person who is seeking employment (whether or not he or she is also registered with the government's Pôle Emploi employment agency), to benefit from specialized accompaniment that includes help with defining a professional project given the constraints of disability, together with assistance with training if necessary, and help accessing various forms of benefit and preparing for recruitment, including contact with employers and follow-up of integration in the workplace following recruitment.

# ANNEX II LIST OF ACRONYMS

| | |
|---|---|
| AAH | *Allocation aux adultes handicapés* - Adult Disability Benefit |
| ACS | *Aide à l'acquisition d'une complémentaire santé* - Assistance to Acquisition of Supplemental Health Coverage |
| Agefiph | *Association pour la gestion du fonds pour l'insertion professionnelle des personnes handicapée*s - National Association for Management of the Fund for Professional Integration of Disabled Persons |
| ALD | *Affection de longue durée* - long-term medical condition |
| AME | *Aide médicale d'Etat* - State medical aid |
| ARE | *Allocation d'aide au retour à l'emploi* - Allowance to assist return to employment |
| ARS | *Agence régionale de santé* - Regional health agency |
| ASI | *Allocation spéciale d'invalidité* - Special disability allowance |
| ASPA | *Allocation de solidarité aux personnes âgées* - Solidarity allowance for elderly persons |
| ASS | *Allocation spécifique de solidarité* - Specific solidarity benefit |
| CAF | *Caisse d'allocations familiales* - Family allowance authority |
| CDAPH | *Commission des droits et de l'autonomie des personnes handicapées* -Commission for the Rights and Autonomy of Disabled Persons |
| CMU | *Couverture maladie universelle* - Universal Sickness Coverage |
| CMU-C | *Couverture maladie universelle complémentaire* - Supplemental universal sickness coverage |
| CNAM | *Caisse national d'assurance maladie* - National health insurance agency |
| CNCPH | *Conseil national consultatif des personnes handicapées* -National Consultative Council for Disabled Persons |
| CNSA | *Caisse nationale de solidarité pour l'autonomie* - National agency for autonomy |
| Corevih | *Coordination régionale de lutte contre le VIH* - Regional coordination of the fight against AIDS |
| COTOREP | *Commission technique d'orientation et de reclassement professionnel* - Technical commission for professional orientation and retraining |
| ESAT | *Etablissement et service d'aide par le travail* - Agency for Assistance through Employment |
| Fiphfp | *Fonds pour l'insertion des personnes handicapées dans la fonction publique* - Fund for the Integration of Disabled Persons in the Public Sector |
| FSI | *Fonds spécial d'invalidité* - Special Disability Fund |
| GRPH | *Garantie de ressources aux personnes handicapées* - Guaranteed Income for Disabled Persons |
| GRSP | *Groupement régional de santé publique* - Regional pole for public health |
| IJ | *Indemnités journalières* - per-diem sick pay |
| MDPH | *Maison départementale des personnes handicapées* -Departmental Agencies for the Disabled |
| MVA | *Majoration pour la vie autonome* - Increased Allowance for Autonomy |
| PASS | *Permanence d'accès aux soins de santé* - Permanent Access to Healthcare |
| PC | *Prestation de compensation* - Measures to support and compensate for disability |
| RMI | *Revenu minimum d'insertion* - Minimum Integration Income |
| RQTH | *Reconnaissance de la qualité de travailleur handicapé* - Recognition of Status as a Disabled Worker |
| RSA | *Revenu de solidarité active* - Active solidarity income |
| SAMB | *Salaire annuel moyen de base* - Baseline average annual salary |

| | |
|---|---|
| Sameth | *Service d'aide au maintien dans l'emploi des travailleurs handicapés* - Agency to promote the maintenance of employment for disabled workers |
| SMIC | *Salaire minimum interprofessionnel de croissance* - Minimum wage |
| TRT-5 | *Groupe interassociatif de lutte contre le sida "traitements et recherche thérapeutique"* - Group associating several associations in the fight against AIDS on "Treatments and Therapeutic Research" |

# RECOMMENDATIONS

As a consequence of the present analysis, the National AIDS Council issues the following recommendations:

## TO CHANGE PERCEPTIONS OF DISABILITY, AND BRIDGE THE GAP BETWEEN ACTORS OF HIV AND DISABILITY:

- Regular campaigns of communication aimed at the wider public must promote the new concept of disability which arises from the law of February 11, 2005, and the new duties that this involves for society. The aim should be to help the public's image of disability evolve beyond visible disabilities alone.

- Consultative bodies involved with disability, and notably the National Consultative Council for Disabled Persons (CNCPH) and the National conference on disability, should become more open to representing disabilities arising from chronic, evolutive pathologies. More generally, actors of disability should rethink their approach to include disabilities that do not result from traditional, recognized forms of handicap.

- Associations and non-profit bodies involved in the fight against AIDS should integrate the question of disabilities, as defined by the February 11, 2005 law, into their agenda, and promote their legitimate role in the consultative bodies involved with disability. To further this aim they should aspire to greater unity in order to speak with a single voice, and should seek possible convergence with non-profit bodies and associations constituted around other chronic, evolutive pathologies.

## TO IMPROVE ASSISTANCE TO PERSONS LIVING WITH HIV AND OTHER CHRONIC PATHOLOGIES BY GOVERNMENTAL BODIES:

- **Regarding Departmental Agencies for Disabled Persons (MDPH) and the National Solidarity Agency for Autonomy (CNSA) as leader of the MDPH network:**

    - MDPH agencies must define a referent person who is trained in the specific issues and problems of disabling, chronic pathologies, with the mission of assisting teams in identifying, reading and evaluating the files of persons with these disabilities.

    - A coordinating physician must be present in every MDPH. The efforts underway in certain MDPH agencies to stabilize their personnel and improve the quality of medical expertise should continue, and should be extended to all MDPH agencies.

    - An effort must be made to sensitize and train MDPH teams and personnel to the specific questions of disabilities arising from chronic, evolutive pathologies.

    - MDPH agencies and related bodies must establish the technical and human means necessary to evaluate requests within a reasonable delay, particularly when, as is currently the case, the delays stipulated by current regulations are rarely respected.

    - Governmental authorities and the MDPH network should initiate further analysis on how to reduce disparities in practice between different MDPH agencies, notably by creating more coherence between structures on a regional level, linked to the creation of Regional Health Agencies (ARS).

    - Commissions for the Rights and Autonomy of Disabled Persons (CDAPH) should progressively integrate representatives from associations of patients living with chronic pathologies. Regarding HIV, the hypothetical regional coordination of MDPH agencies should include representation of Corevihs.

    - Efforts should be made to sensitize personal physicians to the need to take special care in filling out medical certificates for the MDPH. A global approach to all the aspects of disability that may affect the patient's quality of life, based on discerning dialogue with the patient, should be promoted. The MDPH network should work together with associations of the patients concerned (and particularly with associations involved in fighting AIDS) to draw up a document to assist the preparation of such medical certificates.

- **Regarding the Agefiph and Fiphfp funds and the Cap Emploi network:**
    - The Agefiph and Fiphfp should develop deeper analysis of the specific characteristics of chronic, evolutive pathologies, particularly regarding the variability of handicap, in order to develop more suitable assistance to the persons affected.
    - The Agefiph, in its role as leader of the Cap Emploi network, should further sensitize these bodies to the problems of chronic illnesses and particularly HIV, given the implications of confidentiality with respect to employers.
- **Regarding National Health Insurance agencies:**
    - Advisory physicians should be sensitized and trained regarding the specific characteristics of chronic, evolutive pathologies. Training modules and information packages aimed at advisory physicians should be drawn up, and could usefully include expertise from associations of patients affected by disabling chronic pathologies, notably associations involved in fighting AIDS.
    - The criteria to be applied by the advisory physicians should be made more specific and more explicit.
- **Regarding support by government authorities for associations involved in the fight against AIDS**
    - Government authorities, including national and local government, Regional Poles for Public Health (GRSP), and the Agefiph et Fiphfp funds, should become more durably involved in financing associations and bodies that are engaged in developing programs for integrating into society and the workplace persons living with HIV who may be distant from employment.

### TO IMPROVE THE SITUATION OF HIV INFECTION AND CHRONIC ILLNESS IN THE WORKPLACE:

- **Regarding occupational health units**
    - Training for occupational physicians in the specific characteristics of chronic pathologies and the disabilities they entail should be improved, both in terms of initial training and refresher courses. Occupational physicians should be a motor for defining innovative solutions to modify job-descriptions or schedules. More flexible use of the possibility of therapeutic part-time work and 1st category disability pensions should be promoted.
    - The National AIDS Council endorses the recommendations of the Economic and Social Council regarding reform of the system of occupational medicine, aimed notably at reinforcing the independence of occupational health units, clarifying their missions and restoring trust. This analysis and action should be aimed at avoiding the notion that occupational medicine is a selective process at the service of the employer.
- **Regarding employers**
    - Employers should aim to transcend traditional notions of adapting the work environment with ergonomic modifications and equipment to compensate for sensory deficits, and should envision adaptations in terms of rhythms of work and expected levels of performance, in order to respond better to the variability of disabilities arising from chronic illnesses.
    - Innovative solutions will be needed to permit small companies to manage this type of disability, and specific forms of benefit will need to be developed.
    - Sensitization to the difficulties of employees affected by illness and disability, and the struggle to fight prejudice and stigmatisation, should take place at every level of the workplace. Employers, human resource management, unions and workers' representatives should promote information and good practice in this regard.

### TO IMPROVE BENEFITS AND BASIC INCOME FOR UNEMPLOYED DISABLED PERSONS:

- The National AIDS Council endorses the recommendations of the National Consultative Council of Disabled Persons (CNCPH) of April 4, 2007, entitled *To guarantee a basic income to disabled persons* ("Pour la garantie d’un revenu d’existence pour les personnes en situation de handicap.") Benefits to insure basic income for disabled persons should be increased to attain the level of the minimum wage

(SMIC). In the long-term it would be advisable to simplify these measures, whose complexity is a source of disparities, and to create a single basic income.

- The rules regarding attribution of the allowances that constitute basic income should be revised, to avoid the lengthy gaps encountered while awaiting access to this income or when personal situations change, and to insure continuity of payment of the allowance until new income justifying cessation or reduction of the allowance is effectively received.

- In the short term, the planned reform of the AAH should be continued, notably concerning improvement of the rules governing cumulation of the AAH with income from work, mechanisms to minimize threshold effects similar to those effected for the RSA, and consideration of employability.

- The threshold for access to the CMU-C must be modified so that beneficiaries of the AAH have access to this benefit. The procedure for access to assistance with subscription costs for supplemental coverage should be simplified, for persons whose income exceeds the threshold for access to the CMU-C, and information regarding this benefit should be improved.

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