



Chronic illnesses and employment: a novel guide created by those concerned

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Context

The French legal framework supporting employment for people with disabilities does not take into account the specific needs of people living with long-term, chronic diseases such as HIV/AIDS, cystic fibrosis, cancer, or multiple sclerosis. French patient-led NGOs representing several chronic illnesses have thus worked together since 2002 to advocate for specific improvements in policies.

Description

Our inter-NGO guidebook "Chronic illnesses and employment" tells the stories of people affected by a chronic illness, combining both information on patient's rights, difficulties, and especially successful individual coping strategies.

This publication is a fully community-driven endeavour: (1) it responds to specific needs expressed by affected and mobilized communities (2) both content and layout were produced by people affected by chronic illnesses. This process enabled both the co-authors and readers to realize that people affected by different pathologies share similar challenges with regards to employment. This participatory production method aroused strong interest from the employment sector and those affected: 19,000 copies were distributed in 4 months in 2007.

Lessons learned

- Thanks to the participation of affected communities, this guide presents the difficulties encountered, without condescension, and gives a perspective on individual experiences relating to work.
- This testimonial of the daily reality of people living with chronic diseases enabled a far greater acknowledgement of their needs by key decision makers and employers.
- The gravity and the scope of the challenges we reported, the multi-faceted negative impacts of inadequate



"Chronic illnesses and employment, a novel guide created by those concerned, Testimonies & experiences."

employment practices, call for serious changes in both policies and practices.

Next steps

Our guidebook strengthened our legitimacy as advocates on behalf of the needs of people living with chronic diseases and to foster improvement in their quality of life notably in our monitoring of the ongoing implementation of the 2005 new French laws on the social integration of people with disabilities.



"You cannot get the AIDS virus by using a colleague's telephone"

Le virus du sida ne se transmet pas en empruntant le combiné d'un collègue.  www.aides.org

AIDES, a French NGO

Set up in 1984, AIDES is the largest HIV/AIDS community-based organisation in France, with centres in over 70 cities. We support partner organisations in Central and Eastern Europe, North Africa and sub-Saharan Africa.

Our main goals:

- To inform vulnerable people about HIV/AIDS prevention and testing
- To support PLWHAs, (social & professional integration, therapeutic education)
- To advocate for the rights of PLWHAs.



www.aides.org • AIDES is a co-founding member of PLUS

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