
Towards A Better Life: People Living with HIV/AIDS (PWA) in Norway

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Context

*"With HIV infection levels estimated to increase to 30-40 million by the year 2000, the socio-economic impact of the pandemic is expected to be devastating for all countries, and increasingly for women and children. While direct health costs will be substantial, they will be dwarfed by the indirect costs of the pandemic - mainly costs associated with the loss of income and decreased productivity of the workforce. The pandemic will inhibit growth of the service and industrial sectors and significantly increase the costs of human capacity-building and retraining. The agricultural sector is particularly affected where production is labour-intensive."*¹

Addressing HIV as it relates to Agenda 21 and as an environmental issue, whilst prevention is important to minimise the impact of the epidemic, this paper focuses on the needs of people already infected with HIV, in order to "reduce the personal and social impact of HIV infection".²

HIV in the North

While the majority of PWA live in the South, the epidemic is also present in the North. At the end of 2000, it is estimated that 5% of PWA live in Western Europe, North America and Australia/New Zealand.³ Issues relevant to the situation of PWA in these Northern countries are related to the improved prospects many experience as a result of increased knowledge and ability to manage the virus through medication, nutrition, and other means. For many PWA in the North, being diagnosed with HIV now means to be diagnosed with a chronic disease rather than being given a death sentence.

This poses challenges to the organisations for PWA, for the institutions of care, for service providers, and for prevention work. In Norway, a needs assessment was commissioned but the AIDS Association (Pluss-LMA), funded by the Norwegian Foundation for Health and Rehabilitation. The consultancy Kontekst Kommunikasjon carried out the project, titled "A Better Life for PWAs in Norway", which charted needs among PWA in a Northern context. The project concluded with a set of recommendations for action. While this reports focuses on a needs assessment carried out in Norway, the issues raised here may also be relevant to PWAs in Western Europe, North America and Australia/New Zealand.

Challenges

The needs of PWA in the North have, in general, shifted from care towards rehabilitation and recreation. PWA also still need psychosocial support. In Norway, recreation, rehabilitation psychosocial support services may be provided through the public health and social services. The needs assessment revealed that PWH&A experience that needs within these areas are unmet, and awareness about existing services as well as rights is low.

¹ UNDP 1992: Agenda 21, chapter 6, para 11

² UNDP 1992: Agenda 21, chapter 6, para 12, objective j

³ UNAIDS 2000

Stigmatisation and fear of openness leads to unmet needs among PWA

The reasons for unmet assistance and low awareness is not that services do not exist, but rather it is a widespread fear of openness, of discrimination and fear that health and social service professionals, particularly in smaller towns and rural areas, will tell others about HIV diagnosis. This fear of openness is based on personal experiences, and/or "horror stories" told by others who have experienced various forms of violation of rights, stigmatisation and discrimination. Being able to make full use of the existing services and options for rehabilitation, recreation and psychosocial support, requires a degree of openness about the HIV diagnosis. The study showed that fear of openness bars PWAs from making full use of services and treatment, and also from seeking available information.

Longer lives are not necessarily better lives

The new situation where PWAs live longer lives has both positive and negative consequences for infected individuals. In general, the respondents find greater hope from their new situation, but the fear of the future remains ever present. This is partly related to a fundamental scepticism towards the new medication, and partly also to having to adjust to an uncertain future, which previously PWAs did not have to do when the HIV diagnosis was regarded as a death sentence. Having to conceptualise a future one had previously written off is not only a mental challenge, but may also be problematic for example for starting or completing education programmes and employment as an infected adult. In the Norwegian pension system, the eventual pension upon retirement depends on the number of years the individual has had paid employment, on the salary size, and other adjusting factors. Acquiring these pension rights is a real issue for PWAs, and worries about not having these rights are a new challenge to PWAs. Similar challenges have been reported also from North America, where researchers have termed this change the "Lazarus effect" after the man who in the bible was resurrected from the dead.

The Norwegian study respondents, as do respondents in other studies of people using HIV medication, also emphasise problems with side effects of the new medication, as well as fear of negative long-term effects as a result of prolonged medication use. Medication affects individuals differently and is not equally beneficial to all PWAs. The side effects alone make many feel tired and ill. Efforts to assist PWAs therefore have to consider the variation in relation to resources and needs within PWAs.

Solutions/Strategies

Meeting the needs identified in the Norwegian assessment requires targeted action. The recommended actions referred to in this section may therefore not be wholly relevant for other countries where the welfare system is structured differently. However, the recommendations made here hopefully serve as an inspiration and offer some ideas in other contexts, in the South as well as the North.

- **Target groups revisited**

PWAs have traditionally been divided into intervention and outreach target groups based on infection path ("heterosexual", "homosexual", "intravenous drug users"), ethnicity, and other categories. Based on the study "*A Better Life for PWAs*" Kontekst Kommunikasjon recommends that this traditional thinking about target groups be revised. Categories which carry greater meaning would be related to issues such as physical and mental health, economic resources, general living standard, psycho-social network, and contact with other PWAs. These factors often cut across the traditional target groups.

- **National advice and competence centre**

From the end of the 90s, the movement within the health and social services sector in Norway has been towards establishing "competency centres" where knowledge and resources related to a certain

diagnosis or type of work is collected in one place. Kontekst Kommunikasjon recommends that Pluss-LMA develops an independent national competency- and advice centre. The study "*A Better Life for PWAs*" showed that PWAs have difficulty in accessing relevant information, that anonymity is important. Gathering together scattered information and resources in one easily accessible centre, where PWAs would know that anonymity is a priority. Such information would meet a great need. The centre should use paid staff and volunteers at Pluss-LMA with knowledge about HIV. Resources should include a library with available and accessible up-to-date information and literature, as well as a well-maintained website. The centre should incorporate a Rights Centre, where information on all the legal aspects and rights relevant to PWAs is available. The updated library would also be available to members, volunteers, staff, and others related to Pluss-LMA, as well as care providers, people working in the health and social services sector, the media, and others. The centre should also be the basis of HIV prevention efforts.

- Independent advice centre

The study showed that the information that is available is perceived as inaccessible, the barriers to obtain information are high, and the self-perceived degree of knowledge about rights varies, but is mostly very low. Based on this Kontekst Kommunikasjon recommends the creation of an advice centre, independent from the public health and social services. This centre should be part of the national advice and competence centre, and consist of individual advice through meetings with competent advisors, in addition to the possibility of anonymous contact through telephone, e-mail and internet chatting. The advice centre would ensure access to knowledge and information on rights in relation to the public health and social services, and the option of seeking advice anonymously would lower the barriers to seeking help.

- Web-based information and internet chat

Kontekst Kommunikasjon recommends the development of a website with targeted and updated information, in addition to internet chat rooms. Internet-based information will enable those who are too afraid to be open in person about their diagnosis to contact Pluss-LMA, and those who are not open to others in their immediate surroundings to gain access information. The option of anonymous internet chat rooms where PWAs can "talk" with other PWAs would be available to anyone who needed contact with others in the same situation. Also, we have reason to believe that internet chat would be welcomed also by any PWAs who are more open about their status, and provide an open space to chat with others who share this particular diagnosis.

- Courses in openness

As the individual requiring services often themselves have to seek information and subsequently the service, themselves, enabling and empowering PWAs to manage openness is important. Kontekst Kommunikasjon therefore recommends the development of courses for PWAs. The courses should contain information on rights, as well as training in openness about HIV status when dealing with friends, family, colleagues, health- and social service professionals, others who use and work in recreational environments, and the public in general. Courses are also needed for entering/re-entering the labour market. These courses should be part of the national advice and competency centre.

Adapting the existing options for recreational environments

The Norwegian public health service, on application, will cover part of the expenses for patients wishing to spend time in a spa or other approved recreational facility. Some of the participants in the study had spent time at such recreational facilities, and the experiences were extremely varied. Also, knowledge about the possibilities for rest and recreation varied, but was generally poor. The study showed there was however a strong desire for recreational activities but that the need differed when it came to type of recreation. Kontekst Kommunikasjon therefore recommends to adapt 3-5 of the

approved recreational facilities to include PWAs among the patient groups that are catered for. This includes, in particular, working with the staff there to ensure no fear of stigma in relation to the patients' diagnosis. As PWAs are a heterogeneous group, which needs to be taken into account, including when considering how to adapt the necessary facilities.

Actions against discrimination and fear of openness

- Legal provisions against discrimination

In addition to courses enabling and empowering PWAs to manage openness, there is a need for a national legal framework against discrimination. Kontekst Kommunikasjon recommends the adoption of legal instruments against discrimination in the work place similar to those which already exist in Sweden. In addition, as public unemployment services in Norway are locally based, Kontekst Kommunikasjon recommends that PWAs have the option of using the services at a higher administrative level, to increase anonymity.

- Health and social services professionals

The study showed that experiences with professionals and care providers in the public health and social services sector are divided. While some professionals are seen as very competent, this did not hold in all cases. However, such carers are directly instrumental in the lives of many PWAs. Kontekst Kommunikasjon therefore recommends increased awareness of issues related to HIV among professionals in the health and social services sector. It is a challenge that there are relatively few PWAs in Norway, and therefore the motivation to raise awareness throughout the health and social services sector is not as high as it could have been. It is therefore again important that PWAs themselves are able to handle meeting professionals in the health and social services sector, and are aware of relevant rights and the like.

Political and Strategic Work

- Adaptation of possibilities for rehabilitation

Within the Norwegian public care provision, there are several new projects and provisions for rehabilitation, such as physical rehabilitation (after illness, accidents), and rehabilitation into the labour market. Kontekst Kommunikasjon recommend that Pluss-LMA work towards including HIV on the list of conditions to qualify for the various forms of rehabilitation.

- Increasing employment of PWAs

The study shows that PWAs fear that their HIV status is a barrier to seeking work. Kontekst Kommunikasjon recommends that work be done to increase employers' willingness to employ PWAs. Also, Kontekst recommends dialogue with employers to increase awareness of HIV, and also of possibilities for partnerships between the employers and the public services, e.g. to offer subsidised salaries upon employing some PWAs.

PWAs with Special Needs

Groups such as intravenous drug users, the homeless, and to some extent refugees and immigrants, may have problems in addition to their HIV status which are so large that "ordinary" rehabilitation, recreation and psychosocial support are insufficient. Kontekst Kommunikasjon recommends to carry out a separate project to define the needs, and how to meet them, for these groups.

Partnerships

Already, Pluss-LMA is working with the public sector service providers to implement the relevant recommendations for action. This partnership is crucial to achieve the desired results.

Conclusions/recommendations

The main conclusions and recommendations for PWA in Norway are described above. In summary, the principle need among PWAs in Norway and the main barrier to exercising rights and utilising existing services is a deep-seated fear within individuals of social stigmatisation and discrimination. This stigmatisation is also identified as a problem for PWAs globally. Policy, programmes and process dealing with PWAs need to directly address this problem along with the open provision of care and support for all people that carry HIV and AIDs.

References

UNDP: *Agenda 21*, Rio de Janeiro 1992.
UNAIDS: *AIDS Epidemic Update 2000*, Geneva 2000.

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