Privacy, Surveillance and HIV/AIDS in the Workplace. A South African Case Study" Z. Muskat-Gorska

## Interview Mr. Brad MEARS, Chief Executive Officer, SABCOHA, 19.11.2007

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Questions:

- 1. The reasons for collecting data on workers HIV status in the workplace
- Should the value of reporting (monitoring the disease) overweigh the value of confidentiality or the opposite?
- 2. Concerns about confidentiality of HIV related data
- What is the debate on confidentiality like in SABCOHA?
- What are disciplinary actions for unauthorised disclosure in the workplace?
- 3. Does confidentiality play a major role in low VCT and ARV uptake or they are other important factors?
- 4. The way HIV/AIDS data is stored
- Do companies report this data outside?
- How companies monitor who is infected in the workplace through VCT or there are other means of gathering this information?
- Possibilities of collecting HIV information by using other methods of workplace surveillance

Confidentiality of HIV/AIDS data is a huge concern in the workplace in South Africa. In case of workplace HIV/AIDS programs for testing or/and treatment we do not deal with a dual patient – doctor relationship anymore. There is a third party too – the employer. The employer is interested in certain information on HIV positive workers in the enterprise but he is not entitled to all information. The employer need data on the following issues: how his workplace testing or treatment program is going, what is the statistical data on HIV/AIDS is his enterprise in relation to gender, cathegory of employees (managers, workers), etc. The employer may also be interested in information how many employees need the treatment and how many of them is on treatment. Obviously, such interest may create a threat to confidentiality of HIV/AIDS status of individual workers.

However, ethical employers will be very concerned about respecting workers' right to data privacy, being aware that with low perceptions of confidentiality of HIV/AIDS status it will be impossible to succeed with any workplace HIV/AIDS initiative. Also, generally, employers do not ask for individualized data – names of HIV positive workers. In the majority of cases basic data on HIV/AIDS in the workplace – numbers, statistics – will be sufficient.

At the same time, the attitude of business towards HIV/AIDS is subject to change. Big, progressive employers moved away from discriminatory practices that previously did take place in South Africa. However, still cases of discrimination on grounds of HIV/AIDS happen – mostly in the form of dismissal. Currently, many examples come from the agriculture sector.

Confidentiality does play a very important role in low uptake of testing and treatment in the workplace. What is somehow problematic is that confidentiality used to be defined narrowly, while it appears that it is an issue inherently interconnected with workplace matters in a broader context. The changing reality of HIV/AIDS and the way it operates in labour relations brings new challenges for protecting confidentiality of workers' HIV/AIDS status. One of the examples is growing importance of specialised, outsourced companies for running HIV/AIDS testing and treatment programs in the workplace where workers' data privacy rights are subject to new regulations. The crucial thing will be to ensure that these companies can operate freely from any pressure to disclose workers' data on their HIV/AIDS status and that they implement appropriate safeguards in order to secure safety of this data. It is especially important taking into account that these companies are brought to the workplace for specific issue – to provide testing or treatment. They are unable to consider how HIV/AIDS may interrelate with labour relations and lead to direct or indirect discrimination (for instance, getting rid of a peronally detested employee using HIV/AIDS as an excuse). That is why the importance of confidentiality of HIV/AIDS data should be asessed in a broader context.

At the beginning of adressing HIV/AIDS in South Africa both testing and treatment were so stigmatized, that now, even if it is not the case anymore, people are reluctant to indirectly disclose their status by taking adventage of HIV/AIDS initiatives provided by companies. Still, in South Africa there is not enough of open, constructive public debate on the epidemic which continues to be a great tabboo of a public life. One also has to be aware of a traditional, historical conflict between workers and employers that dates back to the anti-Apartheid struggle. Perception of confidentiality is a subjective thing and it is evident that a current South African workplace is to large extent characterised by workers' mistrust in employers. That is why one has to be aware that sometimes even if security of workers' HIV/AIDS data is in place, perceptions of confidentiality of HIV/AIDS status may remain low because of general lack of trust in labour relationships in South Africa. And this is another very important aspect of how confidentiality safeguards operate in the South African workplace. To some extend I would agree that the culture of data privacy is not very well developed, at least in the sense that people give away their data quite easily and are not aware of rights they have.

## Ad. 4.

When it comes to the monitoring of HIV/AIDS in the workplace it seems the argument about the need for more personalized data to evaluate costs and efficiency of corporate HIV/AIDS programs cannot defend itself. The employer can adequately manage HIV/AIDS related risk withouth infringement of its employees privacy rights. From the legal perspective it would be very few circumstances in which the employer would have the unlimited right to invade privacy of individuals for the sake of monitoring. However, there are such cases. For instance, monitoring an employee's activities in order to react in cases of misconduct is a justified right of the employer. In case of video surveillance in the workplace there is no requirement for notifying the worker that his/her work is moniotored and recorded. There were, however, cases that performance monitoring leads to gathering data on HIV/AIDS. Therefore, there a possibility to use workplace surveillance tools to monitor HIV/AIDS in the workplace is created, which might in case of unethical employers lead to discrimination on grounds of HIV/AIDS. For instance, I have anecdotal knowledge on the case in which a camera has been installed in a truck in order to monitor performance and conduct of a driver. The driver has not been informed that he was monitored. It appeared that during the recorded he stopped several times in order to have sex with sex workers. While this was the case of misconduct, inevitably assumptions about his HIV/AIDS status were made, as truck drivers who involve in transactional sex are regarded as main actors in spreading HIV/AIDS.

It has to be clear that safeguards preventing the employer from accessing HIV/AIDS medical records of workers are crucial in achieving higher uptake of testing and treatment.

When it comes to disciplinary sanctions for an unauthorised disclosure of HIV/AIDS personal data by a negligent emloyee, I am not aware of any such cases. However, I am convinced that sanctions against such emloyee would be the strongest possible, from a final warning to immediate dismissal.