



## HIV issues and people with disabilities: A review and agenda for research

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### ABSTRACT

The recent AIDS and Disability Partners Forum at the UN General Assembly High Level Meetings on AIDS in New York in June 2011 and the International AIDS Conference in Washington, DC in July 2012 underscores the growing attention to the impact of HIV and AIDS on persons with disabilities. However, research on AIDS and disability, particularly a solid evidence base upon which to build policy and programming remains thin, scattered and difficult to access. In this review paper, we summarise what is currently known about the intersection between HIV and AIDS and disability, paying particular attention to the small but emerging body of epidemiology data on the prevalence of HIV for people with disabilities, as well as the increasing understanding of HIV risk factors for people with disabilities. We find that the number of papers in the peer-reviewed literature remains distressingly small. Over the past 20 years an average of 5 articles on some aspect of disability and HIV and AIDS were published annually in the peer-reviewed literature from 1990 to 2000, increasing slightly to an average of 6 per year from 2000 to 2010. Given the vast amount of research around HIV and AIDS and the thousands of articles on the subject published in the peer-reviewed literature annually, the continuing lack of attention to HIV and AIDS among this at risk population, now estimated to make up 15% of the world's population, is striking. However, the statistics, while too limited at this point to make definitive conclusions, increasingly suggest at least an equal HIV prevalence rate for people with disabilities as for their non-disabled peers.

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### Introduction

There is an urgent need to consider the impact of the AIDS epidemic on people with disabilities (DESA, 2011; Groce & Trani, 2009; UN, 2010). More than one billion people worldwide live with physical, sensory (deafness, blindness), intellectual or mental health disabilities, or a combination of these (WHO, 2011). The recent AIDS and Disability Partners Forum at the UN General Assembly High Level Meetings on AIDS in New York in June 2011 (UN AIDS, 2011) and at the International AIDS conference in Washington in July 2012 (IDDC, 2012) underscores the growing attention to the impact of HIV and AIDS on persons with pre-existing disabilities (UN AIDS, 2011).

Such attention is welcome but long over-due. There is a bidirectional relationship between disability and HIV and AIDS. Not only can the HIV virus result in disability, but people with pre-existing or acquired physical, intellectual, sensory or mental health disabilities are at risk of HIV. This latter group has largely been excluded from HIV prevention campaigns, clinical outreach efforts and social and economic support schemes, despite the fact that a small but growing body of research indicates that they are at equal risk for HIV infection (Groce, 2003; Hanass-Hancock, 2009a; Rohleder, Braathen, Swartz, & Eide, 2009). In 2009, UNAIDS in collaboration with WHO and the Office of the UN High Commissioner for Human Rights (UNAIDS, WHO, & OHCHR, 2009), called attention to the weak data and lack of data on prevalence and incidence of HIV among persons with disabilities; the need for all HIV programmes to address the concerns of persons with disabilities; and the need for better translation of the existing research into policy and practice.

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In this review, we summarise what is currently known about the intersection between HIV and AIDS and disability with particular focus on people with pre-existing disabilities. This includes HIV prevalence data, data on risk factors and literature that explores the barriers to inclusion of people with disabilities in HIV prevention, research and outreach efforts across the lifespan. We argue here that a better understanding of the prevalence of HIV, as well as insight into the barriers to the consistent exclusion of people with disabilities in HIV and AIDS research and outreach efforts is needed. It is further argued that response to this need must reflect the diversity among people with disabilities in terms of type and severity of disability, age of onset, and prevailing socio-economic and political barriers faced.

People with disabilities are in need of the same HIV and AIDS information, services and supports as all other members of society. They can no longer be an afterthought. The United Nations Convention on the Rights of Persons with Disabilities (UN, 2006), now ratified by more than 125 countries, clearly calls for the inclusion of people with disabilities in all international development and global health efforts. An increasing group of experts now agree with the statement of former World Bank President James Wolfensohn that unless persons with disabilities are included in all development efforts, none of the Millennium Development Goals will successfully be met (Wolfensohn, 2002).

## Background

Thirty years into the HIV epidemic, it remains true that people with disabilities – 15% of the world's population according to the World Health Organization (WHO, 2011) – are rarely mentioned in the HIV and AIDS literature. There are a series of related factors that explain – but do not excuse – why they have been overlooked. Disabled people face all known risk factors for HIV including poverty, lower levels of education and employment, and significant social, economic and political marginalisation (Elwan, 1999; Oliver, 1990). This is made all the more complex by the common but incorrect assumption that people with disabilities are asexual or not sexually active, and thus not in need of sex education (Groce, 2003; Hanass-Hancock & Nixon, 2009; Mulligan & Neufeldt, 2000; Rohleder et al., 2009; Sullivan & Knutson, 2000). Additionally, people with disabilities face attitudinal and physical barriers to accessing health care, which includes accessing HIV prevention services, HIV testing and sexual and reproductive health care (Groce, 2003, 2005a; Hanass-Hancock, 2009a; Rohleder et al., 2009).

Researchers have argued that the general lack of awareness of the vulnerability of people with disabilities to HIV has limited funding for epidemiological work in the area (UN AIDS, 2011; UN AIDS, 2012). Ethical concerns about research on people with disabilities have also disincentivised research, as it can be difficult to obtain informed consent because of communication barriers (for example, in the case of some blind or deaf persons) or mental capacity to consent (in the case of some persons with mental health impairments or severe learning/intellectual disabilities). Furthermore, the stigma associated with disability has led many in the disability community to avoid the issue of HIV and AIDS, fearing the double-stigmatisation of being associated with both disability and HIV and AIDS (Groce, 2005a). A comparable barrier exists in the HIV community where many HIV and AIDS experts and advocates avoid being associated with persons with disability because of their own misperceptions and stigma about disability (Hanass-Hancock, 2009a). For all these reasons, HIV and AIDS research and programmes for persons with disabilities have received little attention despite the long-established risks that HIV poses to vulnerable populations and the strong commitment within the AIDS community to equity and social justice issues.

## Methodology

A critical review of published research on the intersection of HIV and AIDS and people with disabilities was conducted October 2010–March 2011, focussing on literature published prior to March 2011. Due to the interdisciplinary nature of the field and the wide focus of issues related to HIV and AIDS and disability, we chose to undertake a critical review rather than a systematic review of the relevant peer-reviewed literature. Furthermore taking a critical rather than systematic approach allowed us to explore issues and their implications rather than focussing more specifically on the evidence base alone (Gough, Oliver, & Thomas, 2012). Because of the paucity of information in the field, we included all peer-reviewed publications identified. The search encompassed:

- All available epidemiological statistics on HIV and AIDS, and disability papers reporting empirical data (quantitative or qualitative) related specifically to HIV and AIDS, and people with disabilities
- publications of research findings that linked related issues, such as sex education, specifically to HIV and AIDS and disability
- papers addressing HIV and AIDS and disability issues

We searched for literature that focused on HIV and AIDS as it affects peoples with pre-existing disabilities, and excluded literature that focused on the disabling consequences of HIV and AIDS. The disabling effects of HIV and AIDS is a field of research that has evolved independently over time, and there is an increasing merging of these fields as disability organisations, disability researchers and HIV organisations work more closely together. However this has been addressed in other recent publications (Hanass-Hancock, 2009a).

The search was conducted using the following general databases: Google Scholar, Medline, Pubmed, EBSCOhost, Academic Search Premier and Science Direct. Key words included: “HIV”, “HIV/AIDS” and “disability”, “disabled”, “handicapped”, “deaf”, “blind”, “visual impairment”, “physical disability”, “intellectual disability”, “learning disability”, “mental disability”, “psychiatric illness” and “psychological disorder”. We excluded articles that involved participants in treatment solely for substance abuse and their risk for HIV, unless participants had dual mental health and substance abuse diagnoses.

Methodological challenges to obtaining reliable statistics on HIV and AIDS among people with disabilities include the fact that there are differing approaches to defining disability. A medical model defines disability in terms of physical, sensory or psychological impairments caused by an underlying disease or disorder. This view has been challenged by the social model of disability (Oliver, 1990), which argues that disability is the result of social, economic and environmental barriers faced by people with impairments. Influenced by the social model of disability, the World Health Organization developed the International Classification of Functioning (WHO, 2001), which defines disability in terms of the interaction between an individual's physical or psychological impairment, their activity limitations and restrictions on participation. Persons who have impairments may be disabled in some contexts, but not necessarily in others. There is thus a challenge to developing a clear consensus on how to define disability in terms that allow consistent and comparable data collection and analysis on many fronts, including in HIV and AIDS research. Work from the United Nation's Washington Group (UN Statistics Division, 2010) has begun to develop a standardised set of questions that allows for the collection of disability statistics in censuses, helping to build databases that enable multi-country comparability. Our findings reflect this

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