



## 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

complexity. Of those studies reviewed, we found that differing definitions of disability were used (often without defining their terms), but we could detect no relationship between differing definitions and reported findings. The literature we have reviewed is based on a range of definitions and different ways of operationalising disability; this brings challenges to our analyses.

## Findings

A total of 124 research papers and 13 general or specific review papers were found. Of the 124 research papers, 98 used quantitative methods (predominantly questionnaires), 20 used qualitative methods (interviews and focus groups), and 6 used mixed methods (questionnaires and interviews or focus groups). Publication dates were from 1990 onwards, with a slight rise in frequency of publications in the last decade. The majority of articles prior to 2000 focused on persons with mental health disabilities. However, the number of papers in the peer-reviewed literature remains distressingly small. On average over the past 20 years, 5 articles on some aspect of disability and HIV and AIDS have been published in the peer-reviewed literature annually from 1990 to 2000, with a slight increase to an average of 6 per year from 2000 to 2010. Given the vast number of articles on HIV and AIDS in the peer-reviewed literature annually, the continuing lack of attention to HIV and AIDS among this particularly vulnerable population is striking.

The majority of studies were conducted in North America (68 from USA, 1 from Canada) and countries in Africa (18 from South Africa; 6 from Nigeria; 2 each from Uganda and Swaziland; and 1 each from Zambia, Kenya and Cameroon). Four studies were from South America (all from Brazil), 9 from Europe (5 from the UK, 1 from France, 2 from Italy; and 1 from Germany) and 4 from Asia (1 from Israel and 3 from India). Three studies compared data across 2 or more countries (see Fig. 1). This geographical spread (or rather lack of it) may reflect extremely limited interest or funding. However, HIV and AIDS also have significant prevalence in regions where there has been very little research: South America, Eastern Europe and South Asia.

Most studies focused exclusively on persons with mental health disabilities (60%; the majority ( $n = 53$ ) from the USA), intellectual or learning disabilities (13%), and persons who were deaf or hard-of-hearing (12%). Few studies focused exclusively on persons with physical disabilities (3%) or on persons who were blind or had visual impairments (2%), although these groups are represented in those studies that focus on 2 or more disabilities (11%).

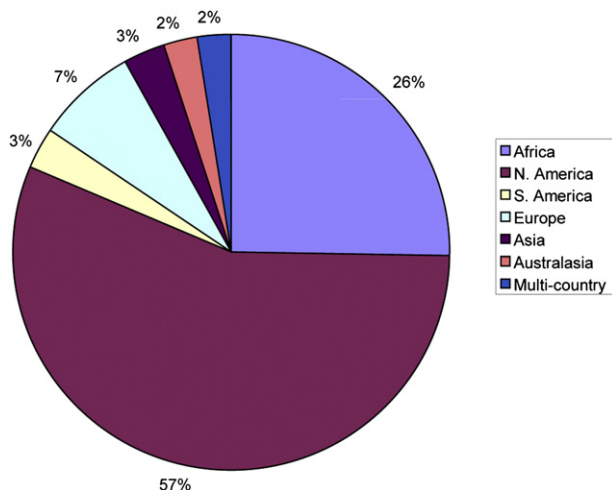


Fig. 1. Proportion of included papers from regions of the world.

## Prevalence studies

Twenty-six studies and one review paper (Cournos & McKinnon, 1997) had statistical data on HIV prevalence. These focused on prevalence within a sample of disability-specific study participants spanning almost twenty years, and give an unclear picture as to prevalence of HIV among people with disabilities. The 26 studies are presented in Table 1.

Most studies made use of convenience sampling, using a single or several specific locations. Sample sizes are generally small, and there was a significantly smaller sample of females in most studies. One of these studies also represents a sub-sample (Sacks, Dermatis, Looser-Ott, & Perry, 1992) of a larger sample (Cournos et al., 1991). The only study which had a comparison group, compared HIV prevalence among deaf and hearing clients at dedicated VCT services (Taegtmeier et al., 2009), finding a lower prevalence rate among the deaf sample, but this rate was similar to the reported national HIV prevalence rate.

These methodological weaknesses, lack of representation of different types of disabilities, and the wide variation in prevalence rates, make the prevalence findings difficult to interpret. If reviewed by type of impairment, evidence from the studies shows that persons with mental health disabilities and hearing impairments are at equal risk as the general population for becoming infected. Among those studies investigating prevalence rate among persons with mental health disabilities, those in USA tended to report that people with mental health disabilities had lower rates of prevalence than persons with mental health disabilities in Africa (South Africa, Uganda and Zimbabwe), which have higher than average prevalence. Studies on those with intellectual disabilities indicate that in those populations studied, these individuals are less likely to test positive, however all studies in the peer-reviewed literature were carried out in residential institutions in developed countries, where individuals with severe intellectual disabilities may be isolated from the general public and closely supervised under tightly regulated systems of care. The only exception here is Pincus, Schoenbaum, and Webber (1990), which included individuals from community settings. These findings may not be representative of persons with intellectual disabilities globally. Indeed, even in considering prevalence rates within institutional settings, it is important to note that individuals with intellectual disabilities living in institutions in many countries face significant issues of sexual abuse, which places them at increased risk of becoming HIV-positive – as is true of all persons with disabilities who live in institutional settings (Groce, 2005a; Groce & Trasi, 2004; Hanass-Hancock, 2009a; Wolfensohn, 2002). Moreover, in both low- and high-income countries, individuals with mild to moderate intellectual disabilities are more likely to live in the community, where they may be sexually active, and at increased risk of being pressured into having unprotected sex or of being sexually abused (Groce, 2005a; Mulligan & Neufeldt, 2000; Sullivan & Knutson, 2000). There is a paucity of data on persons who are physically disabled, blind/visually impaired or multiply disabled. The extremely limited number of studies does not allow us to even begin to make statements about prevalence rates for individuals in these groups. Nor were we able to locate any studies of persons with albinism, considered to be a distinct disability group in sub-Saharan Africa and a group known to be at increased risk for violence and abuse (Groce, 2005a).

We are aware of only one report (published but not peer reviewed) which includes disability in a national survey of HIV prevalence: in South Africa, a recent national household survey (Shisana et al., 2009) indicated an HIV prevalence rate of 14.1% (CI 9.9–19.6%) for those self-reporting as having a disability, compared to 10.9% (CI 10.0–11.9%) among those not reporting

**Table 1**  
Studies of HIV prevalence by type of disability.

Study	Sample population	Total N	% HIV+	Comparison/control group
<i>Mental health disabilities</i>				
Cournos et al., 1991	Anonymous testing of 237 males, 214 females with mental health disabilities admitted to 2 psychiatric hospitals, New York, USA.	451	5.5%	No comparison group. No significant gender differences. Homosexual activity among men and injecting drug use associated with HIV positivity.
Volavka et al., 1991	Anonymous testing of 150 people with mental health disabilities and traceable HIV testing of 365 mental health patients at a state psychiatric hospital, New York, USA.	515	8.9%	HIV associated with drug abuse for both men and women. For females HIV associated with sex with partners who have AIDS, sex with bisexual men, or with drug users.
Lee, Travin, & Bluestone, 1992	Anonymous testing of inpatients with mental health disabilities at a general hospital, USA.	132	14.4%	Strong association between substance use and HIV.
Sacks, Dermatis, Looser-Ott, Burton, & Perry, 1992	Anonymous testing of waste blood products of all people with mental health disabilities admitted to an inpatient psychiatric facility, New York, USA. Number of males and females not reported.	350	7%	No comparison group. 40% of Those testing positive had an unknown HIV status recorded on admission. 80% of These had their HIV status unrecorded upon discharge.
Sacks, Dermatis, Looser-Ott, & Perry, 1992	Anonymous testing of people with mental health disabilities who were new admissions to a private psychiatric hospital, USA.	350	7.1%	Based on data collected by Curnos et al. (1991).
Empfield et al., 1993	Anonymous testing of discarded blood samples of 146 males and 57 females with severe mental health disabilities admitted to a psychiatric unit for the homeless, New York, USA.	203	6.4%	No comparison group. No significant gender differences. Injecting drug use associated with HIV positivity.
Meyer, Cournos, et al., 1993	Anonymous testing of 64 male and 23 female patients with severe mental health disabilities at a psychiatric centre for long-term hospitalisation of homeless persons, New York, USA.	87	5.75%	No comparison group. No significant gender differences.
Meyer, McKinnon, et al., 1993	Anonymous testing of people who were long-stay inpatients at a psychiatric hospital.	199	4%	Prevalence rate comparable to new admissions (5.2% reported in Cournos et al., 1991).
Susser, Valencia, & Conover, 1993	Counselling, testing and self-reported HIV status of 62 men with mental health disabilities at a homeless shelter, New York, USA.	62	19.4%	Some comparisons made with 28 men whose status is unknown, but no significant conclusions could be drawn.
Naber, Pajonk, Perro, & Löhmer, 1994	Counselling and testing of sample of inpatients with mental health disabilities at a university hospital, Munich, Germany.	623	4.8%	No comparison group.
Silberstein et al., 1994	Counselling and testing a sample of 103 males, 15 females with dual diagnosis of mental health disabilities, and substance use, admitted to a psychiatric emergency room, New York, USA.	118	23%	No comparison group. No significant gender differences. African American participants more likely to test positive. Among males, HIV positivity was associated with diagnosis of depression.
Stewart et al., 1994	Anonymous testing of 339 males, 191 females (3 sex not recorded) with mental health disabilities admitted to a psychiatric hospital, Baltimore, USA.	533	5.8%	No comparison group. No significant gender differences. Patients with a self-reported history of intravenous drug use more likely to test HIV+. Homeless patients more likely to test HIV+.
Acuda & Sebit, 1996	Anonymous testing of sample of 87 male, 56 female inpatients with mental health disabilities in psychiatric hospital, Harare, Zimbabwe.	143	23.8%	No comparison group. HIV significantly associated with high education and unemployment.
Rosenberg, Goodman, et al., 2001	Counselling and testing of 327 female and 604 male psychiatric inpatients and outpatients with mental health disabilities recruited from mental health care systems of Connecticut, Maryland, New Hampshire, North Carolina, USA.	931	3.1%	No comparison group. Prevalence reported as 8× higher than general population. Men more likely to test positive than women (ratio of 4:3). Higher prevalence of HIV at larger metropolitan sites.
Klinkenberg et al., 2003	Counselling and testing of participants recruited as part of larger randomised control trial examining effectiveness of assertive community treatment for homeless persons with dual diagnosis (severe mental health disabilities and substance abuse), St Louis, USA.	172	6.2%	Substance uses a high risk factor. No comparison group. Most who tested positive (9/11) were male African Americans.
Rosenberg et al., 2005	Counselling and testing of a sample of 512 males and 243 female inpatients and outpatients with dual diagnosis of substance use disorders and mental health disabilities at mental health care centres in Connecticut, Maryland, New Hampshire, North Carolina, USA.	755	3.0%	No comparison group. Co-infection of HIV with Hepatitis C was associated with severity of mental health problems, drug abuse, urban residence, homelessness, poverty, incarceration, and minority status.

Table 1 (continued)

Study	Sample population	Total N	% HIV+	Comparison/control group
Collins et al., 2009	Anonymous testing of 75 females and 76 males with mental health disabilities admitted to 1 psychiatric hospital, South Africa.	151	26.5%	No comparison group. Women (33.3%) more likely to test positive than men (19.7%). No significant difference between psychiatric diagnostic groups.
Singh et al., 2009	Provider-initiated testing of adult psychiatric inpatients in KwaZulu-Natal, South Africa.	206	29.1% (CI 27.8–32.4%)	No comparison group; used provincial prevalence data instead of comparison group; concluded rates were higher amongst people with serious mental disorder than general population.
Walkup et al., 2010	Recorded HIV status among all Medicaid beneficiaries diagnosed with schizophrenia, in 102 metropolitan areas across 8 states, USA.	8294	1.81%	Wide variations across metropolitan areas.
Maling, Todd, Van der Paal, Grosskurth, & Kinyanda, 2011	HIV test as part of routine medical examination of consecutive sample of 156 males, 116 females with mental health disabilities admitted for the first time to 2 psychiatric hospitals, Kampala, Uganda.	272	18.4%	No comparison group. But higher than general regional prevalence (8.5%). Females more likely to test positive than males.
<i>Learning/intellectual disabilities</i>				
Pincus et al., 1990	Anonymous testing of discarded sera of sample of adults with developmental disabilities recruited from a health facility for developmental disabilities, New York, USA.	241	0.0%	No comparison sample. However, sample included individuals living in both institutional and community environments. No differences found.
Lohiya, 1993	Anonymous testing of all clients (3865 male, 2838 female) with developmental disabilities living in 7 developmental centres, California, USA.	6703	0.16%	No comparison group, but lower than national prevalence (0.4%). No significant gender differences.
Pledgie & Schumacher, 1993	Anonymous testing of residents at an institution for people with developmental disabilities, Delaware, USA.	345	0.0%	No comparison group.
Merrick & Morag, 2000	Anonymous testing of 807 male, 514 female people with learning disabilities (all ages) at 9 (out of 53) institutions for people with learning disabilities in Israel.	1321	0.0%	No comparison group.
<i>Deaf and hearing impaired</i>				
Taegtmeier et al., 2009	Results of voluntary counselling and testing (VCT) of deaf and hearing clients at 3 new VCT sites for the Deaf, Kenya: 1709 Deaf (720 female, 988 male; 1 unrecorded); 1649 hearing clients (745 female, 902 male, 2 unrecorded).	1709 Deaf 1649 Hearing	7% 15%	Deaf participants had significantly lower prevalence of HIV than hearing. Prevalence of HIV among deaf sample similar to reported national HIV prevalence in Kenya (6.7%). Gender differences not reported.
Touko et al., 2010	Voluntary counselling and testing offered to a snowball sample of deaf and hearing-impaired adults from the 5 sub-regions of Yaounde, Cameroon. 57 Males and 44 females tested.	101	4%	No comparison group. 3 Females and 1 male tested HIV+. Prevalence similar to reported general HIV prevalence in Yaounde (4.7%).

a disability. These statistics are difficult to interpret, given the wide and overlapping confidence intervals, but suggest at least an equal HIV prevalence rate for people with disabilities.

#### *HIV knowledge and risk factor studies*

Most studies reviewed investigated levels of knowledge of AIDS, occurrence of unsafe sex and other risk behaviours, as well as access to HIV-related health care among people with disabilities. Surveys and interview studies of people with disabilities and staff or key informants suggest generally low levels of HIV knowledge for people with disabilities (de Andrade & Baloyi, 2010; Bat-Chava, Martin, & Kosciw, 2005; Chopra, Eranti, & Chandra, 1998; Chuang & Atkinson, 1996; Dawood, Bhagwanjee, Govender, & Chohan, 2006; Doyle, 1995; Enwereji & Enwereji, 2008; Goldstein et al., 2010; Gordon, Carey, Carey, Maisto, & Weinhardt, 1999; Hughes & Gray, 2009; Luckner & Gonzales, 1993; Melo et al., 2010; Otto-Salaj, Heckman, Stevenson, & Kelly, 1998; Philander & Swartz, 2006; Strauss, Bosworth, Stechuchak, Meador, & Butterfield, 2006; Wazakili, Mpofu, & Devlieger, 2006, 2009; Yousafzai, Edwards, D'Allesandro, & Lindstrom, 2005), however, few of these studies involved control groups against which levels of knowledge could be compared. In studies that did compare people with disabilities to a sample of non-disabled peers, results indicated significantly lower levels of HIV knowledge (Bisol, Sperb, Brewer, Kato, & Shor-Posner, 2008; Grassi, Pavanati, Cardelli, Ferri, & Peron, 1999; Groce,

Yousafzai, Dlamini, Zalud, & Wirz, 2006; Groce, Yousafzai, & van der Maas, 2007; Heuttel & Rothstein, 2001; Katz, Watts, & Santman, 1994; Koen, Vuuren, Niehaus, & Emsley, 2007; McGillivray, 1999; Ogunsemi, Lawal, Okulate, Alebiosu, & Olatawura, 2006; Otte, van der Maas, & de Boer, 2008; Rurangirwa, Van Naarden Braun, Schendel, & Yeargin-Allsopp, 2006; Yousafzai, Dlamini, Groce, & Wirz, 2004). One study of people with mental health disabilities also reported that the level of HIV knowledge is affected by the level of cognitive impairment (Koen, Uys, Niehaus, & Emsley, 2007).

Studies with people with disabilities or staff and key informants report relatively high rates of unsafe sex and other risk behaviours including substance use, transactional sex, and reported incidence of previous sexually transmitted diseases (Blanchett, 2000; Brown, Kessel, Lourie, Ford, & Lipsitt, 1997; Cambridge, 1996; Carey, Carey, & Kalichman, 1997; Carey et al., 1999; Carey, Carey, Maisto, Gordon, & Vanable, 2001; Carey, Carey, Maisto, Schroder, et al., 2004; Chandra et al., 2003; Chopra et al., 1998; Choquet, Du Pasquier Fediaevsky, & Manfredi, 1997; Chuang & Atkinson, 1996; Collins, Elkington, et al., 2008; Collins, von Unger, & Armbrister, 2008; Davidson et al., 2001; Devieux et al., 2007; Gordon et al., 1999; Grassi, Pavanati, et al., 1999; Grassi, Peron, Ferri, & Pavanati, 1999; Kalichman, Kelly, Johnson, & Bulto, 1994; Katz et al., 1994; Kelly et al., 1992, 1995; Maart & Jelsma, 2010; Meade & Sikkema, 2005, 2007; Menon & Pomerantz, 1997; Menon et al., 1994; Myer et al., 2009; Ogunsemi et al., 2006; Olaleye, Anoemuah, Ladipo, Delano,

& Idowu, 2007; Otto-Salaj et al., 1998; Randolph et al., 2009; Rohleder, 2010; Rosenberg, Goodman, et al., 2001; Rosenberg, Trumbetta, et al., 2001; Smit et al., 2006; Susser et al., 1995; Thompson, 1994; Touko, Mboua, Tohmuntain, & Perrot, 2010; Venable, Carey, Carey, & Maisto, 2007; Walkup, Sambamoorthi, & Crystal, 1999; Weinhardt, Carey, & Carey, 1998).

Substance use (alcohol and drug) was found to be a risk factor, particularly for people with mental health problems, which increased the risk for unsafe sex and HIV infection (Brown et al., 1997; Carey et al., 1999, 2001; Cournois et al., 1991; Davidson et al., 2001; Devieux et al., 2007; Empfield et al., 1993; Essock et al., 2003; Grassi, Pavanati, et al., 1999; Grassi, Peron, et al., 1999; Hoff, Beam-Goulet, & Rosenheck, 1997; Kalichman et al., 1994; Kelly et al., 1992, 1995; Loue, Sajatovic, & Mendez, 2011; Meade, 2006; Menon & Pomerantz, 1997; Otto-Salaj et al., 1998; Rosenberg, Goodman, et al., 2001; Rosenberg, Trumbetta, et al., 2001; Stewart, Zuckerman, & Ingle, 1994; Susser et al., 1995; Volavka et al., 1991; Weinhardt et al., 1998; Weinhardt, Carey, Carey, Maisto, & Gordon, 2001). Two studies found that HIV risk behaviours are associated with severity of mental health disability (Heaphy, Loue, Sajatovic, & Tisch, 2010; Rosenberg, Drake, Brunette, Wolford, & Marsh, 2005), although a third study did not find any significant associations with different mental health disabilities (Collins, Berkman, Mestry, & Pillai, 2009). Depression and post-traumatic stress disorder were also found to be associated with higher HIV risk (Hoff et al., 1997; Silberstein, Galanter, Marmor, Lifshutz, & Krasinski, 1994). Studies of people with mental health disabilities found that HIV risk was higher for those living in metropolitan areas compared to rural areas (Brunette et al., 1999; Rosenberg et al., 2005; Rosenberg, Goodman, et al., 2001). It may also be a possibility that in countries where overall HIV prevalence is lower (higher-income countries), mental health disabilities may be a risk factor for higher rates of HIV, but that this relationship does not hold in lower-income countries; compare Singh, Berkman, and Bresnahan (2009), Acuda and Sebit (1996), and Collins et al. (2009) with the other studies on mental health disabilities.

Findings also highlight low self-efficacy in negotiating safer sex (Brown et al., 1997; Dawood et al., 2006; McGillivray, 1999; Philander & Swartz, 2006; Thompson, 1994; Yousafzai et al., 2005), stigma and social isolation as vulnerability factors for sexual exploitation and HIV risk behaviours (Collins, Elkington, et al., 2008; Collins, von Unger, et al., 2008; Elkington et al., 2010; Rohleder, 2010; Wazakili et al., 2009) and sexual abuse as significant risk factors (Bisol et al., 2008; Groce & Trasi, 2004; Gust, Wang, Grot, Ransom, & Levine, 2003; Hanass-Hancock, 2009b; Olaleye et al., 2007; Randolph et al., 2009; Smit et al., 2006; Yousafzai et al., 2004, 2005). In this regard, females with disabilities were found to be particularly at risk of HIV infection (Hanass-Hancock, 2009b; Morrow, Arunkumar, Pearce, & Dawson, 2007; Stewart et al., 1994; Walkup et al., 1999; Yousafzai et al., 2004).

#### *Access to HIV testing, prevention, and health care studies*

The literature is consistent on the fact that people with disabilities face various physical and social barriers to accessing sexual and reproductive health care, HIV testing and HIV prevention information (Brown & Jemmott, 2002; Chireshe, Rutondoki, & Ojwang, 2010; Desai & Rosenheck, 2004; Fremont et al., 2007; Goldstein et al., 2010; Hanass-Hancock, 2009b; Mallinson, 2004; Neri, Bradley, & Groce, 2007; Philander & Swartz, 2006; Rohleder, Swartz, Schneider, Groce, & Eide, 2010; Smith, Murray, Yousafzai, & Kasonka, 2004; Wazakili et al., 2006, 2009; Yousafzai et al., 2004, 2005), including attitudinal barriers on the part of service providers who may have ambivalent or negative attitudes about the sexuality of people with disabilities or who may not even consider

the possibility that people with disabilities may be sexually active. This seems to be particularly the case for people with learning/intellectual disabilities and mental health disabilities (Collins, 2001, 2006; Coverdale, Falloon, & Turbott, 1997; Katoda, 1993; MacDonald, Murray, & Levenson, 1999; Murray, MacDonald, & Minnes, 1995; Rohleder & Swartz, 2009), and may also be associated with the severity of disability (Fremont et al., 2007; Neri et al., 2007; Yousafzai et al., 2005). HIV policy and provision of HIV education at schools for children and adolescents with disabilities may be insufficient and vary between schools (Deyo, 1994; Rohleder et al., 2010), despite the fact that studies that have evaluated the benefits of peer education and specifically designed HIV prevention education programmes for people with disabilities indicate that such education programmes are successful in improving HIV knowledge and reducing risk behaviours (Carey, Carey, Maisto, Gordon, et al., 2004; Collins, Geller, Miller, Toro, & Susser, 2001; Katz, Westerman, Beauchamp, & Clay, 1996; Kelly, 1997; Osowole & Oladepo, 2000; Taegtmeier et al., 2009). There are few studies and no quantitative reviews on access to AIDS medication, care and support, issues which have already been flagged by disability researchers as areas in which people with disabilities may have been given lower priority (Groce, 2005a; UNAIDS et al., 2009).

#### **Discussion**

While there is a growing body of work investigating HIV as it affects people with disabilities, there remain numerous and conspicuous gaps in our knowledge. Studies have clearly established the fact that the level of HIV knowledge for people with disabilities is generally low. However, we need to know more about how this knowledge translates into practice. Some studies have investigated the prevalence of unsafe sex and other risk factors, but significant gaps exist exploring the various risk factors for HIV across different disability groups. We need to know more about HIV risk for all disability types, and the disability-specific issues and barriers involved.

The majority of existing studies have concentrated on people with mental health problems, learning/intellectual disability or those who are deaf or hearing impaired. Far less is known about the broad range of risk of HIV among people with physical disabilities, those who are blind or have vision impairments, albinism or who are multiply disabled. More data are needed not only on prevalence of unsafe sex, but also about the interplay between disability and the various factors that facilitate sexual risk, such as poverty, substance abuse, and gender inequality. We also need to know more about the interaction between disability, gender, stigma, social isolation and risk behaviours. While there is literature exploring related issues, such as vulnerability to violence and sexual abuse (for example, Groce, 2005b; Grossman & Lundy, 2008; Sullivan & Knutson, 2000), these studies do not specifically link such issues to HIV risk. Furthermore, there are large regions of the world for which little or no evidence on these issues is available, notably South America, Asia and Europe.

Good statistical data are needed on prevalence and behaviours. National HIV and AIDS prevalence studies tend to use antenatal clinic surveillance or population-based surveys (usually household surveys). However, the same issues that limit the ability of people with disabilities to access HIV and AIDS services also limit their inclusion in prevalence research. For instance, research has shown that females with disabilities face numerous physical and attitudinal barriers to accessing fertility and antenatal care (Anderson & Kitchin, 2000; Coverdale et al., 1997; Eide et al., 2011; Rohleder et al., 2010; Smith et al., 2004), so using statistics from antenatal clinic surveillance is likely to exclude significant numbers of

women with disabilities. Population-based surveys that rely on voluntary counselling and testing services may also exclude people with disabilities, as they face barriers to accessing HIV testing (Eide et al., 2011; Enwereji & Enwereji, 2008; Yousafzai et al., 2005). Household-based surveys may reach more people with disabilities, but such surveys would need to include questions that identify household members with disabilities (i.e. Shisana et al., 2009). A further challenge is that even within similar categories of people with disabilities, there is enormous variation in severity of impairment, life history and social and economic support networks.

Comparable research is needed in other areas as well. The literature suggests that there are various attitudinal and structural barriers to care, treatment and support for people with disabilities who are living with HIV or diagnosed with AIDS. Much more research and attention is needed on this. For example, individuals with different types of disabilities will need different approaches to HIV prevention: people with intellectual disabilities may require much more careful explanation of the options for and consequences of voluntary counselling and testing; deaf individuals would benefit by sign language interpretation of HIV and AIDS education, testing and clinical services. In terms of treatment, people with physical disabilities may have difficulty accessing facilities where anti-retrovirals (ARVs) are distributed, challenging their effective adherence to the treatment. In terms of 'positive living' with HIV, those with mental health disabilities may find social interaction and sustaining motivation a barrier to effectively engaging with the 'positive community'. We need to better understand what approaches work best for specific disability groups.

### Conclusion and recommendations

There are several areas that are especially worthy of further research as they may help address vulnerabilities of people with disabilities in regard to HIV and AIDS. HIV and AIDS researchers can help to fill in these gaps. Furthermore, a range of largely unexplored areas of research exists where a solid evidence base, including qualitative, quantitative and intervention studies, are critically needed. The most pressing need is inclusion of a disability perspective in HIV and AIDS research, by including measurements of disability and human functioning (ICF) in surveys and intervention studies, and by including respondents with disability in qualitative studies. Among key specific needs are to:

- Ensure that a full range of disability groups are studied and analysed both on specific disability (impairment) levels as well as using broader concepts of disability reflecting human functioning, activity and participation.
- Use of a broad disability lens to elucidate risk factors for particular groups – for example, with mental health disability, it is not only the disorder itself which increases risk, but also stigmatisation, social exclusion and impoverishment.
- Ensure that research explores issues across the lifespan, so as to include disabled children, disabled adolescents and the elderly, as well as adults with disabilities.
- Ensure that studies address disabled women as a group at particular risk
- Link disability research with known HIV risk factors for the general population, such as poverty, abuse, violence, lack of education and substance abuse.
- Develop and widely disseminate a robust set of interventions and care options for people with disabilities who have become HIV-positive and/or who have developed AIDS – this is a major gap in the literature

- Ensure that research findings translate into health policy revision to promote greater inclusion of people with disabilities and greater sensitivity to their health rights among service providers (MacLachlan et al., 2012). There has been some progress in including disability in national HIV and AIDS policies in countries like South Africa (Department of Health, 2011), but policy development efforts continue to be hampered by lack of data.

It is essential that disability issues be both mainstreamed into current HIV and AIDS research and programming at all levels and also targeted in the form of disability-specific research and programming to allow in-depth exploration of the unique barriers to HIV prevention and HIV and AIDS care among hard-to-reach disabled subgroups. This twin track approach (mainstream/population specific) is routine in many other arenas of HIV and AIDS research. For example, outreach efforts for the general population exist side-by-side with targeted programs for sex-workers or ethnic populations. Disability – a cross-cutting issue – should be approached in the same manner: it is essential that we build a disability component into mainstream HIV and AIDS epidemiological prevalence, prevention and intervention studies. This would provide a clearer understanding of the extent to which person with disabilities may be affected by HIV in comparison to the general population, and how this intersects with other demographic variables such as age, gender, and socio-economic status. Furthermore, by including people with different types of disabilities in general prevalence studies, we can make comparisons across the range of disabilities. With regards to prevalence studies, the recent South African national household survey (Shisana et al., 2009) can serve as an example.

Finally, AIDS researchers are urged to build partnerships with disabled peoples' organisations (DPOs) and disability researchers to further delineate issues, including ethical concerns, definitions of disability, and identification of parameters for further qualitative and quantitative studies.

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