Closing the Gap: Training Health Care Professionals on the Interrelationship of Disability and HIV

Workshop Manual for Participants

September 2012

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Acknowledgements

We would like to thank the Regional AIDS Training Network (RATN) for funding the development of the workshop manual and materials as well as the piloting of the workshops. Thanks must also go to Farzana Alli for managing, supporting and evaluating the workshops.

Further we would like to acknowledge the knowledge development of academics and implementers in this field whose work has contributed to the development of the knowledge displayed in this manual, in particular Nora Ellen Groce, Jill Hanass-Hancock, Stephanie Nixon, Hellen Myezwa, Elisse Zack, Wendy Porch, Kelly O'Brien, Catherine Grant, Ann Strode, Leslie Swarts, Sue Phillpot, Emelia Timpo, Rosangela Berman Bieler, Phillip Coetzer, Jennifer Jelsma, Joanne Potterton, Nicole Hilburn, Leonie van Eggerat, Rene Brandt, Inge Peterson, Rebecca Johns, Paul Chappel, D.N. Bryan, John Meletse, Hendrietta Bogopane-Zulu, Antony Duttine, Phillimon Simwaba, Hamida Ismail, Darryl Barrett and Muriel Mac-Seing.

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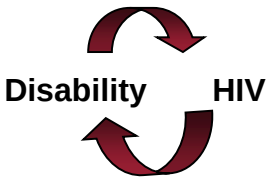
Workshop Agenda

The UNAIDS, World Health Organisation (WHO) and Office of the High Commissioner for Human Rights (OHCHR) *Policy Brief on Disability and HIV (2009)* recognises the interrelationship between HIV and disability, and emphasises that this issue has not received sufficient attention. It stresses the point that people with disabilities are one of the key populations at higher risk of exposure to HIV. It also emphasises that people living with HIV may develop impairments and disabilities as a result of the disease and side effects of treatments.



The interrelationship between disability and HIV has since been recognised by many governments in southern Africa and this is evident in the very recent integration of disability issues in the new national strategic plans. However planning and implementation are two very distinct issues. One of the obstacles in implementation is the lack of skills and expertise with regards to disability and HIV of health care professionals, educators, DPO and NGO representatives and government agents. Therefore, HEARD and its partners have identified capacity building as one of the key areas to address the interrelationship of disability and HIV. Contributing to these efforts HEARD, through its Disability and HIV Project, is providing this workshop. The workshop will provide an overview on the following areas.

- Issues regarding the definition of “disability”
- Vulnerability of people with disabilities to HIV
- Introduction to HIV-related disabilities
- National strategic frameworks and legal obligations
- Implications for HIV services
- Implications for rehabilitation services
- Challenges and good practice examples

This workshop will provide an overview and map out ways for more in-depth study and practical implications.

Day One

8.30 - 9.00	Registration
9.00 - 9.30	Introduction
9.30 - 10.45	What is Disability?
10.45 - 11.00	Tea
11.00 – 13.00	People with Disabilities and HIV
13.00 – 14.00	Lunch
14.00 – 16.00	HIV-related Disability

Day Two

9.00 – 9.30	Recapturing Day 1
9.30 – 10.00	National Strategic Framework on HIV and Legal Obligations
10.00 – 10.15	Tea
10.15 – 11.30	Disability Inclusive Health Care Services
11.30 -12-30	Lunch
12.30 -15.30	Good Practice Examples
	- Accessing HIV services for people with disabilities
	- Inclusion of rehabilitation in HIV services
15.30 – 16.00	Closure and Evaluation

What is Disability?

The World Health Organisation reports that 15% of the world's population are living with various disabilities (up to 20% in resource poor settings) and that the number is increasing due to various factors including the rise in chronic diseases [1, 2]. HIV and AIDS is one of the chronic diseases. This makes people with disabilities the world's biggest minority. Data shows that 80% of people with disabilities live in low-income countries, are poor and have limited or no access to basic services, including education and rehabilitation.

Definition

The United Nations *Convention on the Rights of Persons with Disabilities*, *2009* says "Disability results from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others."

However, the term disability means different things to different people even though there has been a major shift internationally in the understanding of disability in recent decades. The social model, the medical model and the International Classification of Function Disability and Health (ICF) model are the most commonly used models:

The Medical Model

The medical model historically focuses on the dysfunction or impairment of the individual. It conceives disability as the outcome of impairment. Focusing on physical differences the model seeks to cure the impairment rather than address the disabling factors in the environment. It sees people with disabilities as people with bodies that are impaired, do not work and cannot be productive. Often this approach focuses on particular groups such as "the blind" or "the deaf". The medical model has been criticised because it reduces disability to a physical construct when in fact there are many dimensions that contribute to disability.

The Social Model

The social model of disability asserts that an impairment itself is not an obstacle for a person with disabilities, but is a socially-created problem and demands a political and social response. Disability in this understanding is caused by physical barriers, personal attitudes and other features of the social environment. Inaccessibility to buildings and difficulty using transportation are some of the barriers that limit full social participation of people with disabilities. This model seeks to change the environment in which people with disabilities live, work and play. The model focuses on society and not on curing the person.

The ICF Model

Over the last four decades, a gradual shift in the conceptualisation of health and disability from a medical model towards a combined model of disability has occurred. The WHO or ICF model synthesises the medical and social models of disability and creates a "bio-psycho-social" model, which reflects the complex phenomena of disability [2].

Within the ICF framework, disability is understood as a “complex phenomenon that manifests itself at the body, person and social level” [3] and appears on three levels namely body structure/function (impairment), activity level and participation in society. According to this model these three levels are outcomes of interactions between health conditions, the intrinsic features of the individual and extrinsic features of the social and physical environment (see figure 1).

Impairments of body structure or functioning are understood to be problems with the anatomical structure of the body (e.g. a missing limb) or its physical functioning (dementia, deafness, albinism, epilepsy, HIV infection). Depending on environmental (social and physical) and personal factors this condition may or may not lead to activity limitations and/or participation restrictions. Activity limitations are understood as difficulties with executing a task or action (e.g. getting dressed, walking, reading) and participation restrictions are problems relating to involvement in life situations (accessing work or social life).

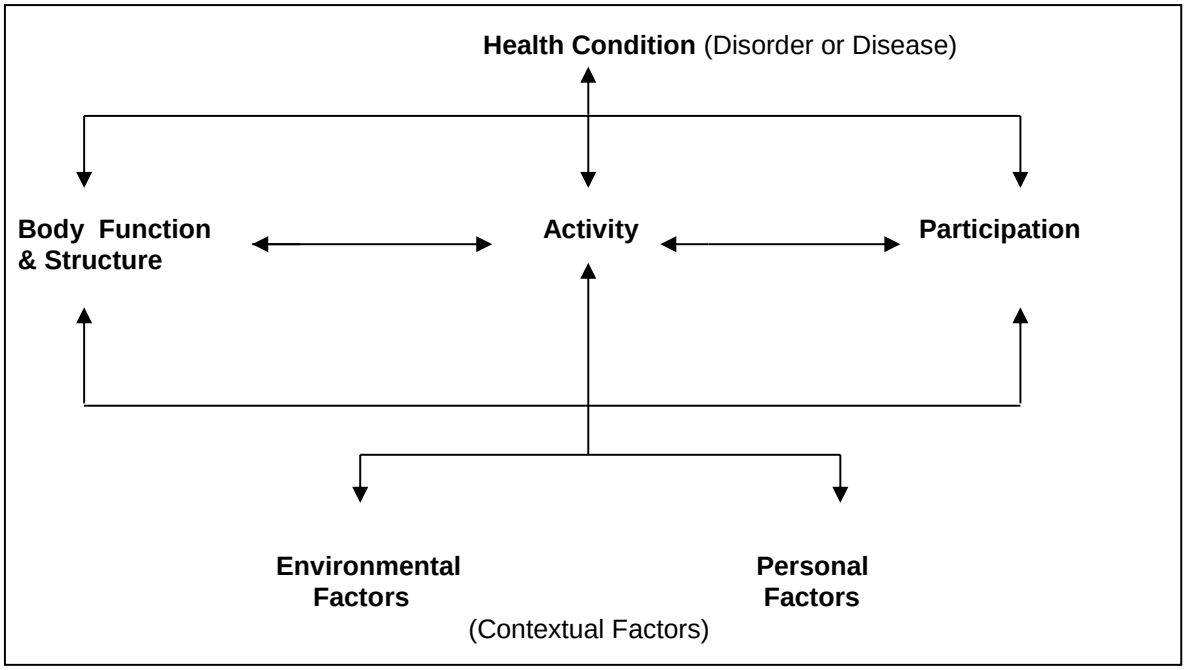


Fig. 1 ICF model of disability (ICF introduction guide p. 9)

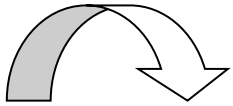
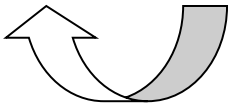
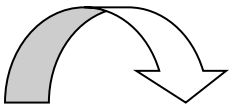
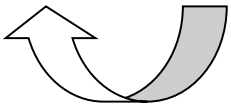
HIV can also be integrated within the ICF model. On the one hand, HIV is a health condition that affects the immune system. With appropriate treatment this might never develop into an activity limitation. However, because of the stigma related to HIV, the person might experience participation restrictions without any major activity challenges or impairments. On the other hand, people living with HIV or AIDS (PLHIV) may also develop impairments/change in body functions (e.g. deafness, blindness, paralysis, HIV- induced dementia, or mental health issues such as depression) that have the potential to develop into activity limitations (disabilities) and/or lead to participation restrictions.

Disability and HIV an Emerging Issue in ESA

The United Nations Programme on HIV/AIDS (UNAIDS) recognises that vulnerable populations with limited access to their basic human rights are often at increased risk of exposure to HIV [4-6]. The limited evidence available suggests that people with physical, intellectual or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection. HIV and AIDS also serves to exacerbate existing difficulties facing people with disabilities by, for example, increasing health, welfare and psycho-social needs, providing additional fuel for stigma and discrimination and further limiting economic opportunities [5, 7]. Additionally, there is a growing understanding that people living with HIV or AIDS are also at risk of developing disabilities on a permanent or episodic basis as a result of their illness [5, 8]. In resource poor settings, very little is understood on this issue, and since the introduction of antiretroviral (ARV) medication it can be expected that there will be a tremendous impact on health systems. Therefore it is necessary to understand the interrelationship between HIV and disability to inform an adequate and sustainable response.

The field of disability and HIV and AIDS has been growing in the last two decades. Attention to the interrelationship between HIV and disability was first drawn in the North in the 1990s with the availability of ARVs [9]. The experience of living with HIV for people who could access these new treatments had shifted from, typically, palliative care to a life of hope combined with uncertainty. Although people were living longer they were experiencing episodic illness and disablement as a result of the secondary effects of HIV (i.e. a broad range of HIV-related conditions that previously had not had time to surface), as well as the side effects of treatment. However, at that time ARVs were not accessible in resource poor settings. In southern Africa they only became available around 2004. We can therefore predict that similar issues will arise which will be exacerbated by the fact that these countries are resource poor settings. In addition there exists a tremendous gap in knowledge around this area in the South.

Figure 2: Evolving Understanding of the Interrelationship of Disability and HIV [9]

Northern experience of the disabling effects of HIV since availability of ARVs in the 1990s:	**Raised attention of the vulnerability of people with disabilities to HIV (2003-2010):**	**Recognition of the interrelationship of disability and HIV (2010 onwards):**
People living with HIV and their experience of disability	People with pre-existing disabilities and their experience of HIV	Exploring synergies and cross-learning, identifying a future research programme
 HIV and AIDS disability	HIV and AIDS disability 	 HIV and AIDS disability 

About the same time that treatment became available in southern Africa the abiding assumption that people with disabilities are at little or no risk for HIV was disproved in the Global Survey on HIV/AIDS and Disability, a seminal World Bank study conducted by Nora Groce in 2004 [7, 9]. As the first of its kind, the study, which collected data from organisations working with people with disabilities in 57 countries across four continents, concluded that almost all known risk factors for HIV and AIDS are increased for people with disabilities, yet they were most often forgotten or left out of HIV programming. This was taken up by the Africa Campaign on Disability and HIV between 2007 and 2008 and has led to a number of studies that have provided more evidence on the vulnerability of people with disabilities towards HIV and AIDS, yet very little is known about good practises and only very few countries had integrated disability in their National Strategic Plans on HIV and AIDS in Eastern and Southern Africa by 2010 [10]. However efforts by UNAIDS, the Global Contact Group on AIDS and Disability (GCGAD) as well as NGOs, research and disabled peoples organisations have pushed for a change in the reviewed strategic plans from 2010 onwards.

It is now more and more recognised that the two fields of disability and HIV have much in common and would benefit from combined advocacy efforts and development, however more evidence, evaluations of good practices and capacity building are needed to address the interrelationships between disability and HIV in our region.

People with Disability and HIV

It has been argued that part of the lack of attention to the vulnerability of PWD to HIV is based on the assumption that PWDs are not at high risk for HIV infection because they are asexual, do not use drugs and are not in danger of sexual exploitation or abuse. However, it is clear that these assumptions are false. People with physical, mental, intellectual or sensory disabilities have recently been recognised as a key population at higher risk of exposure to HIV [7, 11]. The literature argues that people with disabilities are at increased risk of HIV because of the following points :

1. Poverty: People with disabilities are often the poorest members of their communities and the World Bank estimates that persons with disabilities may account for 20% of the poorest citizens in the world.

2. Lack of education: People with disabilities are often excluded from school because they are not considered in need of education, are assumed to be a distraction in class, or are believed to be incapable of learning. Even when in school, children with disabilities are less likely to receive science and health education and more likely to be excused from sex education courses as one does not want to “wake sleeping dogs”.

3. Lack of HIV and "safer sex" information resources: There is a pervasive misconception that people with disabilities are either asexual or oversexed. Although adolescents with disabilities are generally more socially isolated, they have been shown to be as sexually experienced as their able-bodied peers. Reproductive health awareness-raising programmes are known to frequently exclude people with disabilities. Individuals with disabilities are rarely the targets of HIV interventions designed specifically to address their particular prevention needs and are less likely to have access to condoms or other methods.

4. Elevated risk for violence and rape, and lack of legal protection: Abuse among women with disabilities ranges from double to quadruple the rate found among women in general. Approximately 80% to 90% of persons with disabilities are victims of some type of abuse at some point in their lives. Adult women with a disability are more likely than non-disabled females to be physically or sexually assaulted by their partners and women with disabilities are more likely to be subjected to serious violence. However, legal protection is still lacking.

5. Substance abuse: Drug abuse among select groups of people with disabilities is reported to be significantly higher than the general population. Substance use is associated with elevated sexual risk-taking and may also lead to sharing injecting equipment, resulting in increased vulnerability to HIV.

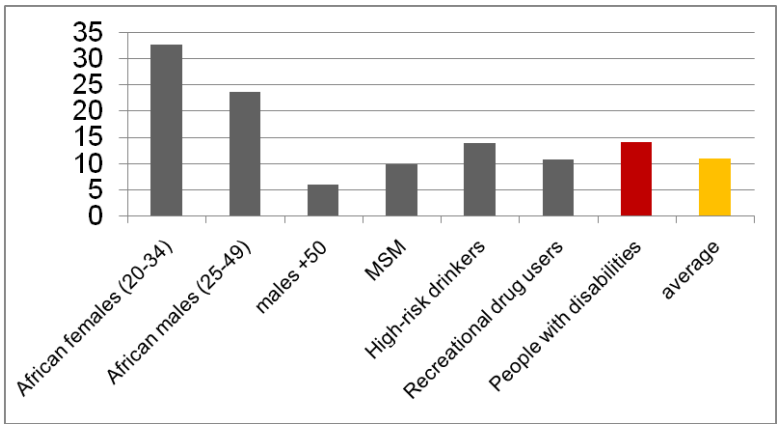
6. Vulnerability of disabled orphans: Children with disabilities who are orphaned have been found to be particularly vulnerable and are less likely to receive the same care and support as their non-disabled orphaned peers.

7. Precarious access to affordable health care: Health care providers have been reported to routinely deny people with disabilities access to HIV testing and HIV and AIDS care. Lower priority is often placed on individuals with disabilities when scarce HIV medications and services are being rationed. Furthermore, people with disabilities face barriers to accessing any form of health care services (e.g., because clinics are often without ramps and Braille or sign interpreters), which can result in other sexually transmitted infections being undiagnosed, further increasing risk of HIV infection.

8. Stigma: Stigma has been associated with HIV, as well as with disability. People with disabilities who become HIV positive may become doubly stigmatised. A further layer of discrimination may also be experienced by people who are not heterosexual.

The few prevalence studies that are available confirm this claim. The national prevalence study from the Human Science and Research Council (HSRC) in South Africa, released in 2008, revealed that at 14.1% (see fig 3), HIV prevalence among the group of people with disabilities was higher than the national average of 10.6% [12]. In this study, the group of people with disabilities showed higher prevalence rates than other key populations such as men who have sex with men. Studies in other African countries on the deaf population similarly indicate that deaf people are as likely (Kenya), if not twice as likely (Cameroon) to be infected with HIV as the general population [13, 14]. The vulnerability of people with disabilities to HIV and AIDS is in keeping with the general recognition that marginalised, stigmatised communities with limited access to their basic human rights are frequently at higher risk of HIV infection and they feel the impact of HIV and AIDS more significantly. Research shows that people with disabilities have higher levels of illiteracy, unemployment and poverty, and are at risk for sexual abuse and assault, factors generally linked to vulnerability to HIV and to a greater impact of HIV infection.

Fig 3: People with Disabilities at increased risk of exposure to HIV [12]



Source: South African National HIV Prevalence, Incidence, Behaviour and Communication Survey, 2008:

Although advocacy efforts have raised the awareness of disability and HIV in the region, people with disabilities are still not fully included in HIV interventions providing prevention, treatment, care, support and impact mitigation. In addition to myths about their behaviour and life experiences, the failure to distinguish between the different needs of people with different impairments (such as the needs of the visually impaired compared with the needs of the physically disabled), the lack of accessibility to health information and services, insufficient training and negative attitudes of health professionals, as well as the social isolation of people with disabilities have all had a negative impact on their ability to access HIV-related health care. It is assumed that the lack of knowledge on how to address these issues as well as still unknown barriers to implementation are responsible for the difficulties in addressing the interrelationship between disability and HIV as the vulnerability of people with disabilities to HIV infection persists, increasing the impact of HIV and AIDS on their lives, once infected or affected by HIV and AIDS.

To sum up, although there is a body of research that argues well the point that people with disabilities are particularly vulnerable to HIV and AIDS, there is little knowledge on how to address this issue in the National Strategic Plans and HIV and disability legislation as well as on good practises that can be taken forward for implementation. This indicates that there is a need for evaluation and implementation research as well as a need for capacity building on disability issues in HIV programming and the dissemination and exchange of good practises.

HIV-Related Disability

It has been suggested that HIV, AIDS and its treatment may cause long term and episodic disabilities, and services need to be prepared for this extra need for rehabilitation particularly in high prevalence areas such as Southern Africa. In their book, “AIDS in the 21st century”, Barnett and Whiteside [15] describe the different waves of the HIV epidemic (see fig 4) which follow logically in time. The first wave describes the increase in HIV-prevalence which is followed by an increase in AIDS cases as the disease progresses within the infected population. Both waves are well described within the biomedical field. However the third wave which focuses on the social and economic impact only became visible at a later stage. This wave describes for instance, the impact of AIDS death. It assumes that period of illness and the death of a person has social and economic implications for the family as well as for society as a whole. With the roll out of ART in Southern Africa the “face of AIDS” has changed from an acute into a chronic illness. However life on treatment does not only mean the prescription of a suitable treatment regime but also the risk of developing disabilities. The HIV epidemic second curve has changed. While countries that have had ART available since the 1990s (e.g. Canada) have already responded to this need, countries in Africa still have to establish the scope of the problem and suitable responses. However given the number of people in need of ART we can predict that southern Africa will have to address the issue of disability on a large scale within the next decade

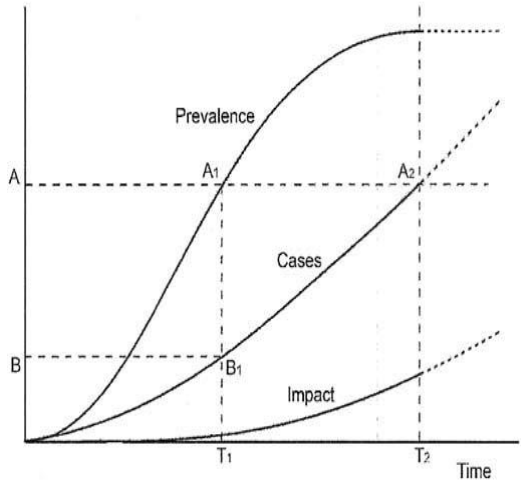


Fig. 4. The tree HIV epidemic curves

Data from several studies point to rising numbers of impairments, which have the potential to develop into disabilities in PLHIV on the body function, activity and participation level. Most commonly, challenges in regards to the respiratory impairments, musculo-skeletal, neuro-cognitive (dementia, neurophathy) and sensory (blindness and hearing impairments) systems, as well as in regards to mental functions, pain and energy levels mobility, self care, domestic activities and work have been described in the literature. A systematic review at HEARD in 2011/12 tried to understand the extent to which these secondary conditions and disabilities effect PLHIV in the era of ART treatment in hyper-

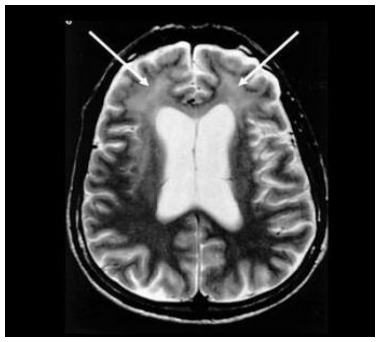


Fig. 5 Non specific white matter changes (Rackstraw 2010)

epidemic countries (all of which are in Southern Africa). The study showed a high incidence of these challenges in PLHIV who had access to treatment:

1. **Mental health disorders are increased in PLHIV:** Many studies have shown that mental health disorders are frequently experienced by PLHIV. Particularly depressions and anxieties (38%-56% of samples), post traumatic stress (15-48% of samples) and alcohol disorder have been recorded in several studies. Women are more prone to experience depressions and anxieties. There is also an indication that these mental health disorders are linked to other challenges, particularly to other health conditions (e.g. stroke) or activity limitation (e.g. reduction in mobility, self care and work).

2. **Mental functions in regards to memory, language and intelligence are affected:** Studies indicate that a significant amount of people on treatment develop HIV dementia (17-37% of sample, hyper-epidemic countries). This loss of intellectual function may affect other areas such as cognitive-motor ability, which includes processing speed, verbal learning/memory, language, psychomotor speed, executive function, and fine motor speed (dominant and non-dominant hands).

3. **Sensory and perceptional functions are affected:** Many PLHIV experience symptoms such as “tingling” and/or “numbness” and studies in hyper-epidemic countries have diagnosed around 30-49% of the samples with peripheral neurophathy. Other sensory impairments have also been reported in regards to vision, taste and hearing. Myezwas and Van As studies indicate an overall prevalence of sensory function problems in 71-83% of their samples (South Africa).

4. **Challenges related to the cardiovascular and respiratory function as well as digestive, metabolic and endocrine system:** PLHIV in hyper-epidemic countries report a number of issues which can be related to the function of several system. Studies provide data that indicates an increased prevalence of respiratory problems (shortness of breath often related to post TB), hypertension and high blood pressure, digestive challenges, and even diabetes. This area has seen very little research and data is only an indication of issues experienced by PLHIV.

5. **Issues related to the genitourinary and reproductive system:** PLHIV have reported issues in regards to the urinary and sexual functions. Again this is an under researched area. Only renal impairments have been explored rigorously in the region. These studies indicate a prevalence of renal impairment in 1-2% of PLHIV. Sexual and reproductive functions might be affected to a larger extend (e.g. Van As study shows 32%). However research is lacking in hyper-epidemic countries.

6. **Impairments of the neuromusculoskeletal movements:** PLHIV have been found to experience neuromuscular problems, particularly the loss of

muscle power as well as fine and cross motor skills. Children living with HIV have also been found to experience developmental challenges. For instance Jelsma and Furgeson's work indicates that 66% of children living with HIV experience motor developmental delays – much more than children without the infection.

7. **Skin problems:** Skin and hair problems have been reported by PLHIV. This seems to be the case for people on treatment as well (5-8%). Skin problems can cause irritation but are also often linked to stigma and discrimination.

8. **Mobility problems caused by a number of impairments associated to HIV:** One of the main results of HIV-related impairments is related to the reduction of mobility levels. Studies have captured this with different tools but generally indicate that 40-56% of PLHIV experience significant challenges with walking, lifting and moving objects. This has effects in their ability to perform tasks but also the ability to access health and other services and is therefore also relevant to adherence.

9. **Self care problems associated to HIV-related disability:** Studies also indicate challenges associated with self care. PLHIV experience problems while using the toilet, dressing or washing themselves.

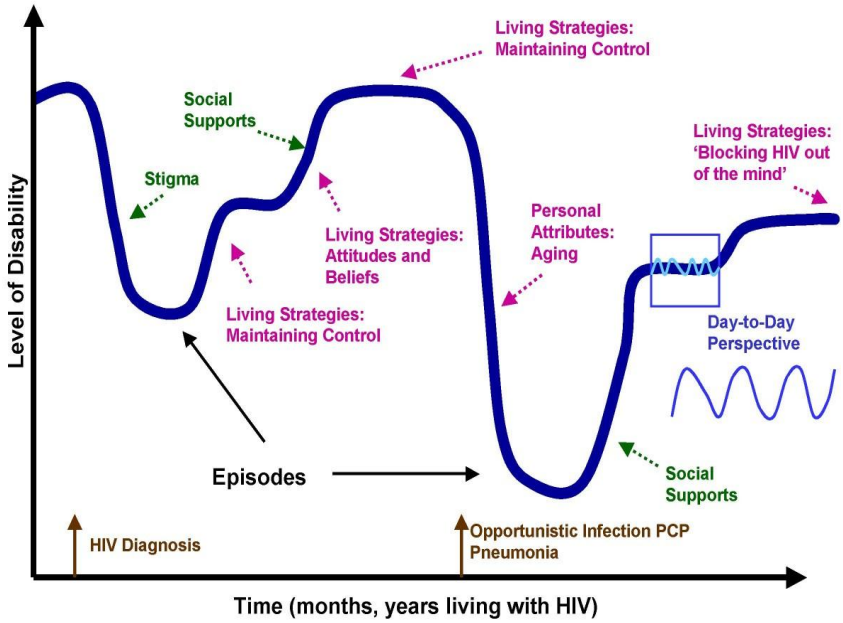
10. **Domestic activity challenges associated with HIV-related disability:** Studies report on challenges related to domestic activity as well. PLHIV who experience disability find it challenging to look after others, provide food, clean the house or tend the garden. Often other household members, including children, have to take over these tasks.

11. **Work and related activity limitations:** Studies also indicate challenges related to work and related activities. Most often mobility changes, pain and fatigue force people to retire from work. More severe disabilities (e.g. blindness, extreme fatigue) also force people to cease informal work or other income generating activities such as gardening or begging. In the absence of a social support system these people enter a vicious cycle of disability and poverty where the one elevates the other.

12. **Stigma and participation restrictions are increased:** PLHIV experiences of stigma have been well described in the literature. However very little data is available in regards to stigma of PLHIV who develop disabilities. The Sepo study (ref workshop report) revealed that disability stigma is much higher than HIV stigma and that the stigma associated with disability restricts people's participation and activity in society much more than their HIV status. PLHIV who experience disability might experience stigma when visiting health services, in community activities (e.g. church or community gatherings) and from family and friends. Women with disabilities often also experience rejections from their partners and might have to look after children by themselves.

Episodic Disability

Episodic disability is a concept that was developed by Kelly O'Brien and colleagues when researching PLHIV in the Canadian context. It refers to the episodic nature of disability as experienced by PLHIV (see the graph underneath) [16, 17]. Research indicated that PLHIV experience good and bad days in which the challenges related to HIV and its treatment play out differently. This resulted in the development of the episodic disability framework. This framework accounts for the ups and downs while living with HIV as well as challenges related to uncertainty, particularly in regards to the future.



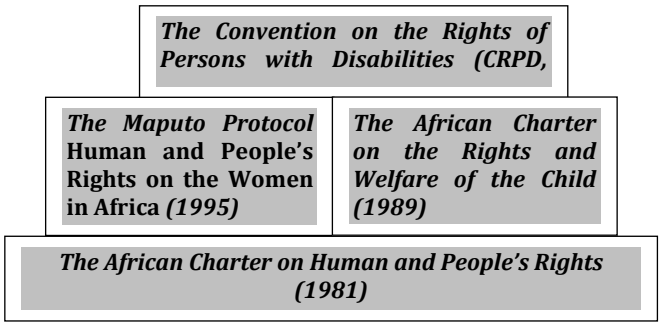
Disability and Health Care Workers in resource poor Settings

Research shows than health care workers experience challenges with addressing the double burden of HIV and disability particular in resource poor settings with high HIV prevalence [18, 19]. Health care workers find it challenging to 1) identify disabilities beyond the medical model of impairments 2) deal with the workload and limited availability of human resources 3) cope with the double burden of HIV and disability emotionally. Health care workers identify a lack of training and resources as well as a need to develop coping mechanisms for their own well being as urgently needed responses to HIV and disability. Public health services should therefore develop strategies to: 1) train health care workers on disability and HIV 2) use resources for instance in a task shifting model to support health care delivery 3) develop efficient disability-inclusive systems including referrals and follow ups 4) develop a staff wellness programme 5) link up to development initiatives e.g. social work, food security programmes, work adjustment interventions, community based rehabilitation etc.

National Strategic Plans and Legal Obligations

Rights to access services and to include PWD within society have been laid out in several documents which are binding for African countries. These include the African Charter on Human and People's Rights, 1981 ('the African Charter'), the Protocol to the African Charter on Women's Rights, 1995 ('The Maputo Protocol') and the African Charter on the Rights and Welfare of the African Child, 1989 ('African Children's Charter'), as well as the recent international Convention on the Rights of Persons with Disabilities, 2006 (CRPD) [20].

Figure 8: Building blocks of disability rights in Africa



The CRPD includes several articles which are relevant in the context of HIV and disability (see box below).

Figure 9: Key provisions in the CRPD relevant in the context of disability, HIV and AIDS [10]

- Article 5 protects the rights of all persons to equality, prohibits discrimination on the basis of disability and guarantees to persons with disabilities equal and effective legal protection against discrimination on all grounds *e.g. include reference to protection of rights of PWDs in NSP*
- Article 8 provides for States to take measures to raise awareness and foster respect for the rights of disabled people, and to combat stereotypes, prejudices and harmful practices relating to persons with disabilities *e.g. include interventions for the rights protection of PWD in the NSP*
- Article 9 promotes accessibility for disabled people, and requires State Parties to take measures to ensure access to the physical environment, transportation, information and communications and to facilities and services e.*g. include provision for adaptations and disability specific services in NSP*
- Article 12 provides disabled people with equal rights to recognition as persons with legal capacity before the law *e.g. provide for the disability assistance in justice system*
- Article 13 requires State Parties to ensure effective access to justice for disabled people
- Article 16 requires State Parties to take measures to protect disabled people from exploitation, violence and abuse *e.g. address sexual abuse of PWD in the NSP*
- Article 22 protects disabled people from unlawful invasions of their right to privacy, including the privacy of personal, health and rehabilitation information *e.g. address confidentiality issues for PWDs*
- Article 24 requires State Parties to recognise the rights of disabled people to *education e.g. provide accessible HIV information and sexuality education*
- Article 25 provides persons with disabilities the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability
- Article 26 provides for State Parties to take appropriate measures to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life *e.g. address HIV related disability and access to rehabilitation for PLHIV*
- Article 27 recognises the rights of disabled people to work on an equal basis with others *e.g. include PWDs in the NAC structures*
- Article 30 requires State Parties to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the UN Convention*. e.g. use disability indicators in national surveys*

Another key document for the implementation of disability inclusive HIV services is the *National HIV and AIDS Strategic Plan* (NSP). NSPs set out a country's response to HIV and AIDS, providing for the needs of those infected, affected and vulnerable to HIV and AIDS. As a result, NSPs are a critical determinant in the allocation of national resources towards HIV and AIDS. In many instances the funding, resources and human capacity that will be devoted to the national HIV and AIDS responses will be utilised within the context of the strategies described in the NSP. Where an NSP is silent on an issue, it is possible that the issue will not receive national attention. The general structure of an NSP might look as follows:

Situation Analysis

Structure and General Approach

Guiding Principals

Priority Areas (old) / Strategic Objectives (new)

4.1 Prevention

4.2 Treatment, Care and Support

4.3 Monitoring and Evaluation

4.4 Human Rights

New: Operational Plan

Some countries might also have additional disability sector plans complementing the general NSP. There is also a disability inclusive NSP framework available which can guide countries in regards to how to include disability within their framework or plan – see appendix 3.

If your country has ratified the CRPD it is obliged to implement it. Therefore you are bound by the law to include people with disabilities in all your activities!

The next chapter provides you with some useful tips on how to make the CRPD a reality in the context of HIV and AIDS.

Accessing HIV-Services for People with Disabilities

Ideally people with disabilities should be included in mainstream settings. Any intervention, structure or service should be guided by two key principles described in the UN Convention on the Rights of Persons with Disabilities, namely, “Universal Design” and “Reasonable Accommodation”.

Universal Design

Is understood as designing “products, environments, programmes and services so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (CRPD). Building ramps within a school or providing mobile clinics in tents are examples of such universal design.

Reasonable Accommodation

Means “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others…” (CRPD). Providing a wheelchair, information in Braille, sign language or simplified HIV information for people with mental or intellectual disabilities are such adaptations.

Adaptations that require no or little extra resources:

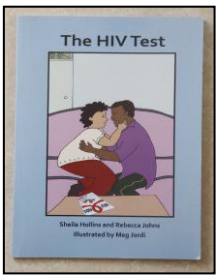
Practically, service providers can improve the accessibility of facilities through using the concept of “universal design” e.g. install crucial services on the ground floor of buildings, using different perception channels in the design of prevention interventions (visual, auditory and touch). Training of VCT counsellors, that already takes place, can include sensitisation around disability issues, address misconceptions about people with disabilities and raise awareness of additional needs.

***Adaptations that require resources*:**

These refer to minor to moderate adaptations within already existing services. Recommended adaptations focus on structural changes to facilities, such as building ramps or providing mobile VCT clinics in tents as opposed to caravans (concept of universal design). Similarly, these types of interventions make HIV prevention material accessible for people with sensory disabilities through providing material in Braille, broadcasting HIV messages on TV with sign interpreters and through including schools for children with special needs and institutions for people with mental health problems in awareness campaigns (concept of reasonable accommodation). It is crucial to include these into the NSPs to raise resources for these adaptations.

Examples: Adapting VCT

The HIV test for people with intellectual disabilities



Sheila Hollins and Rebecca Johns booklet, “The HIV Test” explains in pictures the HIV test and the meaning of results to people with intellectual disabilities. This intervention includes informed consent.

_____
_____
_____

Sign language at the clinic level

Zambia’s sign language poster helps health care providers to remember basic signs around HIV

_____
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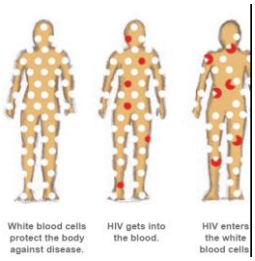
Examples of Adapting Treatment and Care

Simplified explanations on HIV infection



GALA’s “Are your Rights respected” comic illustrates the different stages of HIV in simple pictures for people with hearing impairments/ deafness.

_____
_____
_____

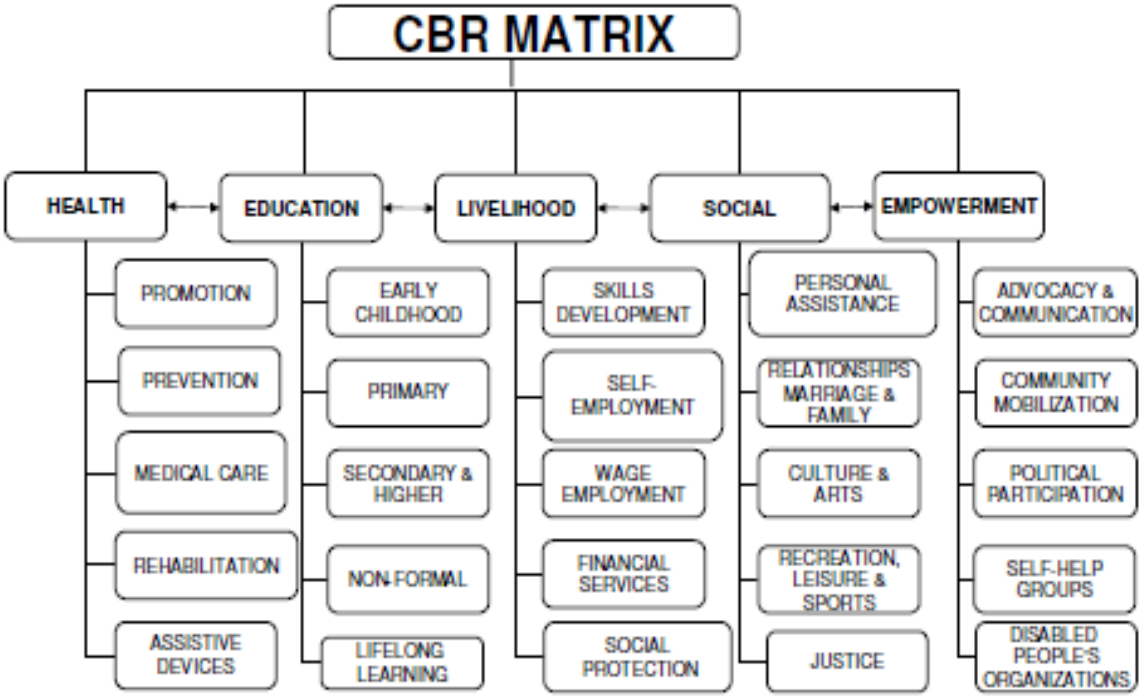
Medicine packaging for the visually impaired

Medical packaging, tablets and labelled containers can include Braille to facilitate accessibility

_____
_____
_____

Rehabilitation and Disability

Rehabilitation is more than just the provision of therapy. It is designed to facilitate the process of recovery from injury, illness, or disease to as normal a condition as possible as well as to adapt and develop an enabling environment so as to accommodate disability. This change in definition of rehabilitation - away from a medicalised model - is most notable in the recently developed Community based rehabilitation (CBR) guidelines [21]. CBR was originally developed by the World Health Organisation as a strategy to improve access to rehabilitation services for people with disabilities in resource poor settings through optimising the use of local resources and mobilising local communities. CBR has now evolved into a multisectoral strategy to address the broader needs of people with disabilities [21]. This strategy includes a community based approach that includes health, education, livelihood, social participation and empowerment (see CBR matrix below). Any rehabilitation approach should be developed with this broader concept in mind.



In order to access the full CBR guidelines go to:

http://www.who.int/disabilities/cbr/guidelines/en/index.html

HIV-related disabilities and rehabilitative care

The CBR matrix includes a column related to access to health. In the context of HIV all five pillars are important to address HIV-related disability:

1. Promotion of health including mental health (wellness approach)
2. Prevention of co-morbidities of HIV (impairments such as mental health, neurocognitive disorders etc., activity limitations and participation restrictions)
3. Access to medical care beyond ART (availability of physical access such as ramps at hospital, treatment of pain etc.)
4. Access to therapy and rehabilitation (physiotherapy, occupational therapy, adaptation of work and home placement etc.)
5. Access to assistive devices (e.g. wheelchairs, Braille writers etc.)

The therapy rehabilitation component has seen very little attention in resource poor settings. However access to ART has changed the lives of many thousands of people by preventing AIDS defining illnesses and prolonging life expectancy. ARV treatment has led to a dramatic reduction in mortality and morbidity, less intense utilisation of healthcare resources, and an increase in quality of life for many. However, the impact of living with HIV infection over many years intertwined with side effects of ARV have led to an evolving and more complex pattern of health care needs. The Canadian Working Group on HIV and Rehabilitation (CWGAD) identified the following HIV-related health concerns (impairments and disabilities) and how they relate to different rehabilitation streams [22, 23].

1.	Diarrhoea, weight loss, “wasting”	- graded rehabilitation
2.	TB, respiratory secretions	- respiratory rehabilitation
3.	Pain, weakness, muscle imbalance, joint stiffness	- musculoskeletal rehabilitation
4.	Hemiparesis , Hypertonia	- neurological rehabilitation
5.	Visual Impairments	- visual rehabilitation
6.	HIV-dementia	- cognitive rehabilitation
7.	Weakness, tiredness	- managing fatigue
8.	Depressions, anxiety	- Managing mental health disorders, wellness approach, laugh therapy, lifestyle management
9.	Loss of mobility and activity levels	- Vocational / workplace rehabilitation

Disability Approaches

Disciplines involved in rehabilitation

Including HIV related disability in HIV care requires the cooperation of several disciplines such as nursing, physiotherapy, occupational therapy, speech therapy, community workers, home based care, mental health care, psycho social support and most of all people with disabilities themselves. Apart from the human resources, screening and referral systems are a vital part of this cooperation:

Simplified disability indicator (Washington Group)

Example of feasible disability indicator
Because of a health problem:

1) Do you have difficulty seeing even if wearing glasses?
2) Do you have difficulty hearing even if using a hearing aid?
3) Do you have difficulty walking or climbing stairs?
4) Do you have difficulty remembering or concentrating?
5) Do you have difficulty with self-care such as washing all over or dressing?
6) Using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others)?

Response categories:
No - no difficulty; Yes - some difficulty; Yes - a lot of difficulty; cannot do at all

Other possible tools for screening and diagnosis of disability suitable for the African context

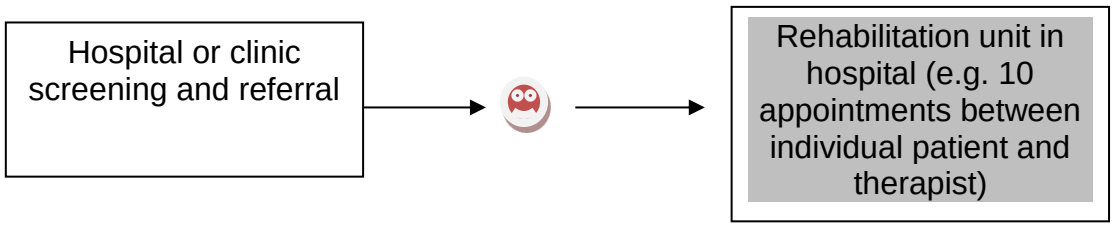
Sheehan disability scale	Simple and very short disability scale
ICF-Checklist	Comprehensive disability tool (see appendix 4)
WHODAS 2.0	Comprehensive disability tool
SRQ 20	Mental health screening tool (see appendix 5)
DSM V	Comprehensive mental health diagnostic tool
IGMST	The Infant Gross Motor Screening Test (appendix 6)
NDT-HIV	HIV Neuropathy Diagnostic Toll (appendix 7)

Different Structures of Rehabilitative Care

Once diagnosed, patients need to be linked to rehabilitation. In resource poor settings the structure of rehabilitative services might have to be thought through more innovatively. Here are three different ways of structuring rehabilitation service delivery:

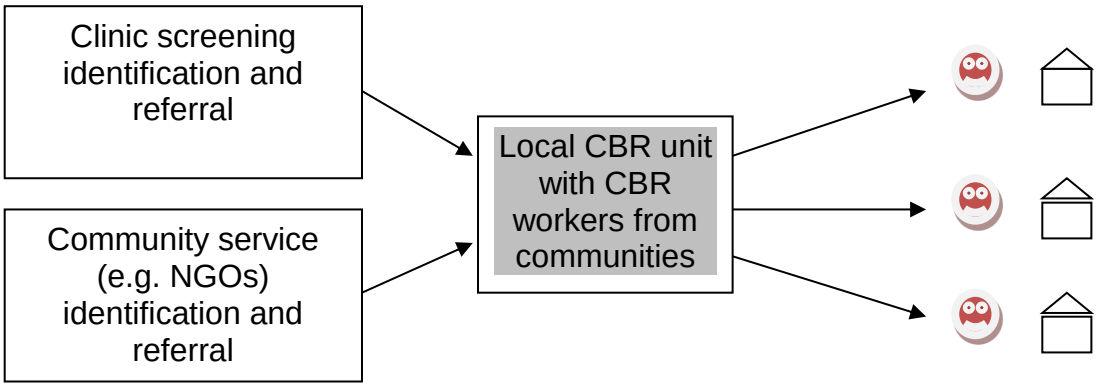
1. **Traditional clinical setting**

   This is useful for resourced urban setting where professional therapists are available. The patient will be referred to a rehabilitation or mental health care unit and be provided with a set of sessions appropriate to address his or her condition. This approach follows often a medical model.



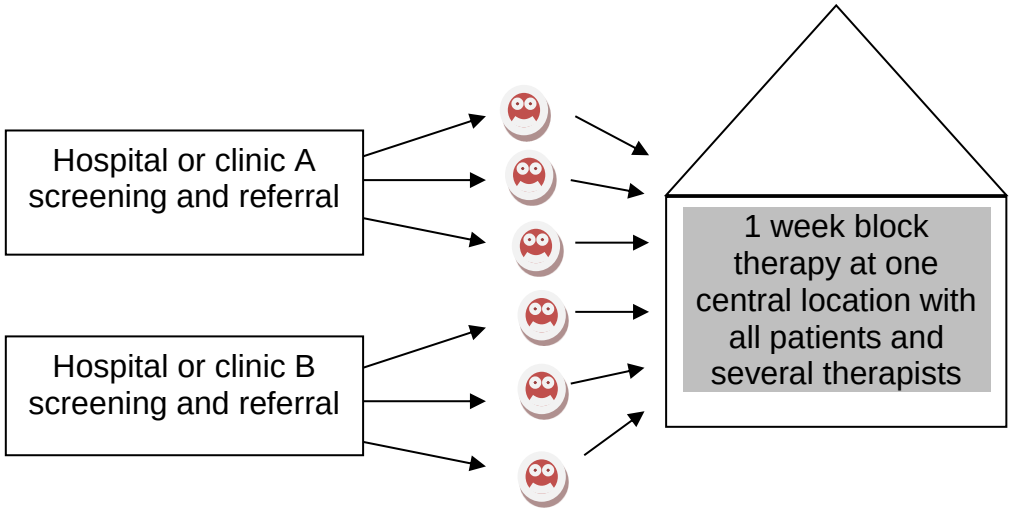
2. **Included in Community Based Rehabilitation**

   CBR has been developed for resource poor settings in urban & rural area were only a few or no specialists are available. A community worker visits the home of the patients and identifies and addresses the individual needs. This is a holistic approach and involves more than rehabilitative therapy.



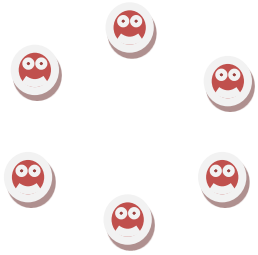
3. **Adapted as block therapy approach**

This might be an alternative in resource poor settings particularly in semirural or rural areas, where professional therapists are more scattered and scarce but available. The approach can also increase patient participation as patients come together for a block setting or therapy sessions. This approach can increase adherence to therapy but might be limited in reaching out into communities. It might be very strong in combination with CBR.



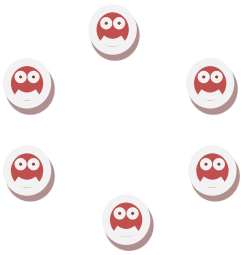
4. **Group therapy**

This approach is often used to address mental health disorders such as depression and anxieties in resource poor settings using Interpersonal Therapy, Problem Solving Theory or Cognitive Behavior Therapy. It can be used in a task shifting model where less qualified staff is trained to provide care and support.



5. **Support groups**

Support groups are useful in resource poor and rich settings. They facilitate community involvement and empowerment of participants.



Useful Resources and Links

HEARD resource centre: www.heard.org.za/african-leadership/disability

Hesperian books and downloads: http://hesperian.org/books-and-resources/

UN Enable: http://www.un.org/disabilities/default.asp?id=1560

Source resources: http://www.asksource.info

UNAIDS: http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

CWGHR: http://www.hivandrehab.ca/

Download rehabilitation guides for HIV-related disability here:
http://www.heard.org.za/african-leadership/disability/hiv-related-disability#books

- IAS 2010 Vienna, *Principles of Physical and Cognitive Rehabilitation in HIV Disease. Handbook to accompany the workshop: Physical and Cognitive Rehabilitation Follwing Complications of HIV Disease: Designing and Delivering Services in Different Settings*. 2010: Vienna.

- Canadian Working Group on HIV and Rehabilitation, *E-Module for Evidence-Informed HIV Rehabilitation*. 2011: Canada.

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23. Canadian Working Group on HIV and Rehabilitation, *E-Module For Evidence-Informed HIV Rehabilitation*. 2011: Canada.

Appendices

Appendix 1 Checklist for Accessible Health Care Services

Appendix 2 CBR Extract / Example

Appendix 3 Disability Inclusive NSP Framework

Appendix 4 ICF-Checklist

Appendix 5 SRQ 20

Appendix 6 The Infant Gross Motor Screening Test (IGMST)

Appendix 7 HIV Neuropathy Diagnostic Tool

Appendix 8 Abuse Board in isiZulu

[i] Angola, Burundi, Democratic Republic of Congo, Malawi, Mozambique, Rwanda, Seychelles, South Africa, Swaziland, Uganda

[ii] Botswana, Kenya, Mozambique, Namibia, Tanzania

Appendix 1 Health Services Checklist

The following checklist provides you with some guidance in order to make your health services more accessible and disability friendly. Please answer yes/no/not sure if your facility is designed is an accessible and disability friendly manner. Please tick the last column "things I can change/influence" if you feel that you can influence or change these aspects.

Is your health care facility designed universal?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Ramps to access your buildings and outside areas				
Crucial services on the ground floors				
Doors that fit a wheelchair and open easily				
Wheelchair accessible toilet				
Railings along the corridors or outside areas				
Directions on key areas in Braille (e.g. lifts, signposts)				

Does your health facility accommodate special needs?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Disability desk at the entrance area				
Preferable treatment so people with disabilities don't have to stand in long cues				
Sign language interpretation and information in pictures for the deaf				
Information in Braille or in audio format				
Beds that accommodate physical disabilities through height adjustments particularly in the maternity ward				
Simplified information for people with intellectual disabilities related to counseling				
Simplified information for people with disabilities related to treatment				
Simplified information for people with disabilities related to abuse				
Medication boxes with symbols, pictures or Braille to accommodate special needs				
Staff who have a disability				

Is your staff trained to screen for disability and refer to the right services?				
Have your staff been exposed to the following:	Yes	No	Not sure	Things I can change/influence
Anti-stigma training focusing on disability and HIV				
Training on sign language interpretation and Braille				
Training course focusing on the interrelationship of disability and HIV (sensitization)				
Training on health rights of people with disabilities				
Training to screen for disability including mental health in general services such as ART				
Referral systems to rehabilitation including Community Based Rehabilitation				
Staff who have a disability				

Is your health service linked to poverty alleviation for people with disabilities?				
Are your health services linked to the following:	Yes	No	Not sure	Things I can change/influence
Back to work programs for people who acquired a disability				
Food security programs that include people with disabilities				
Sheltered employment				
Referral system to social work, disability grants or business loans				

Is your HIV program linked to disability services and rehabilitation?				
Do you have the following:	Yes	No	Not sure	Things I can change/influence
Referral system from disability services to reproductive health services and VCT				
Screening tools to identify disability including mental health problems in your ART program				
Referral system from ART and VCT program to rehabilitation and mental health services				
Rehabilitation department is trained and equipped to address HIV-related disability				

Is your health service linked to community services?				
Are your health services linked to the following:	Yes	No	Not sure	Things I can change/influence
Home Based Care				
Community Based Rehabilitation				
Food security programs				
Livelihood programs that focus on people with disabilities				
Disabled Peoples Organisations				
NGOs that focus or include people with disabilities				

Appendix 2 CBR Extract from: ***World Health Organisation, 2010. Community-based rehabilitation: CBR guidelines. Towards Community-based Inclusive Development. Malta: WHO. Supplementary booklet p. 26-28***

Reaching disabled populations

Inclusion of people with disabilities in HIV/AIDS programmes and services

Many disabled people may not be included in mainstream HIV/AIDS programmes and services because it is often believed that is it too expensive or too difficult. However, there are many ways in which CBR programmes, disabled people's organizations, HIV/AIDS advocates, educators and policy-makers can support their inclusion. Many practical ideas are provided under Suggested activities but, in general, these involve the following:

- facilitating access to mainstream HIV/AIDS programmes and services which target the general population;
- adapting mainstream HIV/AIDS programmes and services to enable inclusion and participation;
- developing and implementing disability-specific interventions for people who cannot be reached by mainstream HIV/AIDS programmes and services.

It is important to remember that combinations of these measures will be required to reach all people with disabilities.

Rehabilitation

Rehabilitation becomes increasingly important for people who may be experiencing disability as a result of HIV/AIDS. Rehabilitation related to HIV/AIDS can slow down deterioration and enable people to achieve and maintain independence (*5*). Rehabilitation will not be covered in detail here as it is addressed in the Health component; however, it is important to understand that, at the community level, CBR can play a key role in addressing the functional problems that people living with HIV/AIDS may experience. In addition, it is important to consider other support and other aspects of rehabilitation, e.g. vocational rehabilitation, which may help a person with HIV-related disability to maintain a healthy and productive lifestyle.

Facilitate access to HIV prevention, treatment, care and support

CBR should work towards addressing the barriers that limit the full participation of people with disabilities in HIV/AIDS prevention, treatment, care and support in the following ways:

- making people with disabilities and their family members aware of the HIV/AIDS programmes and services being offered in their communities and making sure that they are aware that they have a right to attend;
- ensuring HIV/AIDS programmes and services are physically accessible, e.g. CBR programmes can encourage HIV/AIDS programmes and services to move to accessible meeting places or provide advice and assistance regarding adaptations;
- encouraging HIV/AIDS programmes and services to show disabled people in posters, billboards or other materials designed for the general public, e.g. showing a wheelchair user or a blind person with a cane alongside people without disabilities;
- working together with disabled people's organizations to advise HIV/AIDS programmes and services on ways of making simple adaptations to their interventions to ensure that messages are understood by people with disabilities, e.g. passing condoms around during education sessions so that blind participants can feel what they are like and how they work;

- giving information and education materials on HIV/AIDS to people with disabilities who are at risk, to ensure they are being reached;
- working together with disabled people's organizations to advise HIV/AIDS programmes and services on ways of adapting existing materials to make them accessible, e.g. deaf people may require text captioning or sign language interpretation, blind people may require Braille or tapes, people with intellectual impairment may require pictures;
- working together with disabled people's organizations to develop new programmes, services and materials for people with disabilities who cannot be reached by those designed for the general population, e.g. developing education sessions specifically for people with disabilities;
- providing practical assistance, e.g. transport, to improve access for people with disabilities and their families to mainstream services;
- ensuring people with disabilities and their families are provided with appropriate follow-up, e.g. treatment, care and support, after becoming aware of their HIV-positive status.

BOX 12 Uganda

A young woman manages HIV with timely help

In Uganda, a young woman who was deaf had a sexual relationship with a HIV-positive man. She became pregnant, and the man took no responsibility for the relationship or the child. Family members became concerned that she might have contracted HIV, and took her to an HIV/AIDS counsellor. She tested positive, and arrangements were made for her to receive antiretroviral drugs. Now she and her baby (who did not test positive) are doing well; she takes her medication regularly, is working and is also helping out at home. Her family now encourages other families with disabled family members to access HIV/AIDS information and services.

Include people living with HIV/AIDS in CBR programmes

As CBR communicates a strong message of inclusion, programmes should address the needs of people living with HIV/AIDS who may experience disability. Some people living with HIV/AIDS may require access to specialized services, such as rehabilitation and assistive devices. CBR can facilitate this.

Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS

Framework for the Inclusion of Disability in the National Strategic Plans on HIV and AIDS

Context and Approach

The World Health Organisation (WHO) estimates that 15% of the world's population, [2, 3] have a disability, making People With Disabilities (PWD) the world's largest minority [4]. It is estimated that the number of PWDs is increasing "due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life"[4]. Eighty percent of PWDs live in resource poor settings, where they have difficulties in accessing the most basic services to accommodate their needs [2, 4]. With the signing of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) [1], many countries have now committed to providing services that are accessible to and inclusive of people with disabilities, including services for the prevention, treatment, care and support of HIV and AIDS.

> *Disability* is more than a medical phenomenon, it is also socially constructed. The CRPD (2008) defines disability as a "result from the intersection between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis"[1].

The growing available evidence suggests a strong interrelationship between HIV, AIDS and disability. First, people with physical, intellectual, mental or sensory disabilities are as likely, if not more likely, to be at risk of HIV infection. They have 1) insufficient access to HIV prevention information, (2) are sexually active and therefore might engage in unprotected sex, (3) are at increased risk of sexual violence, in particular women and girls with disabilities and (4) have less access to treatment services [1, 5-7]. This increased risk is reflected in the few HIV-Prevalence Studies that include people with disabilities, which suggest that infection levels are equal to or higher than the national average [8-10], and that girls and women with disabilities are particularly at risk [7].

Second, it has been argued that people living with HIV (PLHIV) experience disability as a result of HIV-related stigma and discrimination that they experience[7].

Third, there is increasing evidence that PLHIV may experience HIV-related disability either as a result of HIV, AIDS or, as a side-effect of HIV-related treatment [11-14]. HIV-related disability can result from a diverse range of HIV-associated conditions affecting the body such as neurological conditions resulting in strokes, cardiovascular system changes that result in heart attacks, musculoskeletal problems related to osteoarthritis and accelerated osteoporosis, changes in sexual function, changes in the digestive system, HIV dementia, mental health problems, as well as problems with vision and hearing.

> Within the convention *universal design* is understood as designing "products, environments, programmes and services so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" [1]. Building ramps within a school or hospital is such a universal design as it means that people with physical disabilities should have access to such buildings without assistance.

> *Reasonable accommodation* means necessary and appropriate modification and adjustments, not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others…" [1]. This means for instance providing a wheelchair or a sign interpreter for people with disabilities would be a form of reasonable accommodation.

However, despite the growing evidence on the interrelationship between disability and HIV, PWD have largely been excluded from the national response to HIV and AIDS and existing related frameworks. National Strategic Plans (NSP) often fail to identify the vulnerability of people with disabilities to HIV as well as the reverse relationship of PLHIV to disability [15-17]. Inclusion in this framework allows a human rights-based approach, based on disability rights set out in the CRPD, and its principles of universal design and reasonable accommodation. Additionally, the UNAIDS International Guidelines on HIV/AIDS and Human Rights (UNAIDS, 2006) is a guiding tool for the rights of persons living with HIV/AIDS.

The UN Convention on the Rights of Persons with Disabilities (CRPD) states that State Parties need to "enable persons with disabilities to live independently and participate fully in all aspects of life". Therefore, "State Parties shall take appropriate measures to ensure persons with disabilities on an equal basis with others, have access to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas". To achieve this goal the convention has two guiding principles: (1) universal design and (2) reasonable accommodation. The UNAIDS (2006) International Guidelines on HIV/AIDS and Human Rights recommend that states adopt a rights-based approach to HIV and AIDS. It provides concrete guidelines to

states on legislative and policy measures to reduce HIV-related stigma and discrimination and to create an enabling legal and regulatory framework that reduces vulnerability to HIV and mitigates the impact of HIV on those affected, in particular amongst vulnerable populations. The rights articulated in these two international documents form the basis for this framework.

1. **Purpose**

This framework is a tool to guide the development and review of NSPs across the globe in terms of their disability-inclusiveness, and to realize the commitments of the CRPD and the International Guidelines on HIV/AIDS and Human Rights in advancing important policy frameworks in the context of HIV and AIDS. The framework, its language and its content, has been developed in alignment with regional and international commitments relating to HIV and to disability. It reflects the structure and format of current NSPs and includes step by step guidelines on integrating disability into plans and programmes at different levels. As such, it may provide guidance, accountability or can be used as a template.

It may guide the development or review of NSPs by governmental entities such as the National AIDS Council (NAC), Ministries of Health, Welfare and Social Services, Justice, Constitutional Development and other related ministries, as well as disability advisors. It can be used in conjunction with the framework for women, girls and gender equality [18]. The framework can also support civil society participation in and mobilisation around NSP development and review by important organisations such as Disabled Peoples Organisations (DPOs). Furthermore, Civil Society Organisations (CSOs) can use the tools and links to hold governments accountable in relation to disability inclusiveness.

2. **Background and Guiding Principles of an NSP** (1/3 page)

An NSP's background analysis needs to include HIV and disability issues such as:

- Information on incidence and prevalence of HIV amongst people with disabilities (PWD)

- PWD, in particular girls and women with disabilities, as a vulnerable population
- An accurate description of the impact of HIV and AIDS on PWD
- An understanding of the specific vulnerabilities of people with disabilities
- An understanding of the disabling impact of HIV upon those infected
- A quantitative analysis of HIV-related disability found in this particular context

The CRPD (2008) as well as the UNAIDS International Guidelines on HIV/AIDS and Human Rights (2006) emphasise a rights-based approach towards disability or HIV/AIDS. The following key principles should form part of a disability inclusive national framework to address HIV and AIDS:

- Inclusion of PWD in the national response to HIV and AIDS
- Protection of the rights of PWD and the prohibition of unfair discrimination based on HIV and disability
- Provision of accessible HIV-related prevention, treatment, care and support services accommodating the needs of PWD and using the principles of equality, non-discrimination, universal design and reasonable accommodation
- Provision of information and training on the rights of PLHIV and PWD as well as provision of accessible legal services
- Inclusion of disability in mainstream research, monitoring and surveillance of the epidemic

3. **National Framework to respond to HIV and AIDS**

Each NSP tends to include detailed provisions for the national institutional framework to govern the response to HIV and AIDS. These structures and processes need to involve people with disabilities (PWD). Representatives of people with disabilities should be:

- Included on national multi-sectoral structures set up to guide and oversee the national response to HIV and AIDS (e.g. as a key sector in the National AIDS Councils)
- Involved in the design, implementation, monitoring and evaluation of the national response through various mechanisms

Traditionally, people with disabilities are marginalised. A large number of these persons are among the world's poorest. The national framework needs to provide formal mechanisms to facilitate ongoing dialogue and input from the disability sector. Disabled Peoples Organisations (DPOs) may need capacity building to participate effectively. Support for the development of this infrastructure should be included in the national framework.

4. Priority Areas and Strategies of an NSP

4.1 Human Rights Approach – Equality and Non-Discrimination

NSPs often include protection of the rights of people living with HIV (PLHIV), those affected by HIV and AIDS and vulnerable populations at higher risk of HIV exposure. Rights-protection aims to reduce stigma and discrimination on the basis of HIV and AIDS, ensure that PLHIV have full access to their rights and also to reduce vulnerability to HIV infection amongst vulnerable populations. Rights-based protection in an NSP should include protection on the basis of HIV and disability. In addition, NSPs often mention the special protection of vulnerable populations, which should include people with disabilities (PWD). The NSP needs to provide for various measures to protect and promote equality and non-discrimination on the basis of disability and HIV. Measures may include, amongst others:

- Reviewing laws and policies to protect the rights of people on the basis of disability and HIV
- Developing education programmes that increase understanding and reduce stigma and discrimination against PLHIV, PWD and other vulnerable populations
- Strengthening appropriate and accessible access to justice for PLHIV and PWD (e.g. through the provision of legal support services)
- Strengthening mechanisms to monitor and enforce the rights of PLHIV and PWD, and
- Training health care and other service providers on the rights of PLHIV and PWD

4.2 Health Related Services

All NSPs identify specific priority areas in relation to prevention, treatment, care and support in order to reduce the spread of HIV as well as manage the impact of HIV and AIDS on those infected and affected

by the disease. All prevention and health services should recognise the barriers to access to services and reasonably accommodate the needs of people with disabilities. Prevention, treatment, care and support programmes therefore need to be provided in an accessible and appropriate format through:

- Developing universal designs of services such as the inclusion of ramps in buildings
- Developing specialised formats such as material and packaging in Braille, sign language interpretation and simplified information to compensate for intellectual challenges
- Including the provision of rehabilitative and mental health services for people living with HIV who experience HIV-related disability
- Including measures to address HIV and disability-related stigma and discrimination within health services
- Developing a disability sector plan that provides more detailed and practical guidance on how to implement disability inclusive services
- Providing budget allocation for disability services

4.3 Legal Support Services

NSPs need to include measures to create an enabling framework to protect and promote human rights of people infected and affected by HIV and AIDS and people with disabilities. For example, NSPs may:

- Provide for the inclusion of information and training in regards to the rights of person with disabilities as well as interventions to reduce stigma and discrimination
- Address the provision of access to justice for people with disabilities and those affected by HIV
- Include disability specific support to access justice in the context of HIV and AIDS

4.4 Research, Monitoring and Surveillance

Most NSPs identify research, monitoring and surveillance as a priority area. The participation of people with disabilities in the design, analysis and delivery of monitoring and research is critical. This section of the NSP needs to include disability and ensure the following are included:

- Disability indicators in national surveys, so it is easy to determine HIV-prevalence in people with disabilities as well as risk behaviour and gaps in service delivery

- Disability indicators in the treatment of people living with HIV (e.g. ICF)
- Indicators on the impact of programmes and policies on people with disabilities
- Participation of people with disabilities in the design, analysis and delivery of research
- Demonstration of the long term transformative processes in terms of disability and social norms
- Demonstration of the effectiveness of disability inclusive or specific programmes

5. **Resource Mobilisation**

Operationalizing the principles described above will only occur if resources are mobilised for a disability inclusive approach. Ideally, this requires budgetary allocations throughout the NSP or its operational plan. Examples of the types of programme activities that should be included in the budget are:

- Adapting prevention messages to meet the special needs of such impairments as blindness, deafness and intellectual disability
- Accommodating the special needs of PWD within National AIDS Council structures (e.g. sign interpreter); and
- Undertaking a baseline study to establish the number of PWD
- Capacity building of NGOs, DPOs and health care providers
- Providing accessible services e.g. sign interpreters
- Providing legal support to PWD
- Providing rehabilitation and mental health services for PLHIV
- Ensuring that language is not a barrier in our outreach to the varied populations served

The activities and related costs might be challenging for countries that have already adopted their new NSP or are in resource constrained settings.. Nevertheless countries could work incrementally towards resource mobilisation for a disability inclusive approach through developing:

- An additional disability sector plan or approach that also identifies opportunities for resource mobilisation;
- Partnerships with the disability community through NGOs working with PWD and DPOs (Disabled Peoples

Organisations). This should focus on enabling organisations to submit successful proposals to agencies such as the Global Fund or other international donors. Many of these agencies have developed disability policies in the past years and are therefore obliged to include disability in their development work. Article 32 of the CRPD also requires state parties (also donor countries) to develop “inclusive and accessible” development programs and to provide “technical and economic assistance” as well as “capacity building” in regards to disability; and

- Links with existing state programmes on disability which may be able to reallocate resources to HIV issues.

Finally, countries could also in the interim undertake activities which have limited resource implications. For example, NGO partnerships could focus on the inclusion of these organisations in already existing structures and programmes as well as encourage capacity building for existing structures on the rights of PWD.

6. **Step by Step guidelines (or a roadmap to inclusion)**

This section provides a road map for the inclusion of disability and attempts to map out goals for countries on different levels of the pathway.

6.1 *Initiating Inclusion of Disability* (initiation step)

- Signing and ratifying the Convention on the Rights of Persons with Disabilities (CRPD)
- Including disability as a sector within the National AIDS Council structures (minimal costs for accommodating special needs)
- Commissioning baseline research to provide a situation analysis and ideas for feasible next steps (research one-time costs)
- Mobilising partnerships and resources to develop a disability sector plan/strategy
- Networking and sharing good practices across a region (minimal start up costs)

6.2. *Domesticating CRPD into law and national frameworks* (developing legal and other norms on disability step)

- Domesticating the CRPD into legal frameworks, laws and policies

- Capacity building around disability and HIV
- Developing a disability sector plan and submitting it to funders
- Developing integrated pilot projects on disability and HIV

6.3 *Developing feasible approaches* (towards integration step)

- Integrating disability into the National Strategic Plan (situation analysis and priority areas)
- Allocating resources to disability in key strategic areas (in budget and/or operational plan)
- Integrating disability indicators into national surveys and prevalence studies

6.4 *Monitoring and Implementation of disability inclusive programmes* (optimal inclusion step)

- Developing monitoring and evaluation tools
- Annual reporting on statistics in relation to disability and HIV
- Mainstreaming disability into all relevant programmes such as prevention, treatment, care, support and surveillance

7 Resource Websites

UN Enable http://www.un.org/disabilities/default.asp?id=1560

HEARD Resource Centre http://www.heard.org.za/african-leadership/disability

Source resources http://www.asksource.info

UNAIDS:http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf

8 Contributing organisations

This framework has been developed by the Global Contact Group on AIDS and Disability (GCGAD) NSP task group in cooperation with UNAIDS. It has been inspired by the Framework for Women, Girls, and Gender Equality [18] and the Health Economics and HIV/AIDS Research Division (HEARD) NSP review [16, 19, 20].

We would like to thank all who contributed to the development of the disability and HIV NSP framework in particular the core drafting team Catherine Grant (HEARD), Dr. Jill Hanass-Hancock (HEARD), Ann Strode (School of Law, The University of KwaZulu-Natal) as well as the NSP task group members Darryl Barret (Barrett Advocacy and Training), Steven B. Estey (AIDS-Free World), Prof. Nora Ellen Groce (University College London), Martine Mangion, Canadian Working Group on HIV and Rehabilitation (CWGHR), Muriel Mac-Seing (Handicap-International), Phillimon Simwaba, Disability, HIV and AIDS Trust (DHAT) and Dr. Emelia Timpo, Joint United Nations Programme on HIV/AIDS (UNAIDS).

9 Appendices

- HEARD NSP analysis tool to download at http://www.heard.org.za/downloads/inclusion-of-disability-in-nsps-in-southern-and-eastern-africa-analysis-tool.pdf
- HEARD NSP analysis guide to download at http://www.heard.org.za/downloads/inclusion-of-disability-in-nsps-in-southern-and-eastern-africa-analysis-guide.pdf

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ICF CHECKLIST

Version 2.1a, Clinician Form

for International Classification of Functioning, Disability and Health

This is a checklist of major categories of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization . The ICF Checklist is a practical tool to elicit and record information on the functioning and disability of an individual. This information can be summarized for case records (for example, in clinical practice or social work). The checklist should be used along with the ICF or ICF Pocket version.

H 1. When completing this checklist, use all information available. Please check those used:
[1] written records [2] primary respondent [3] other informants [4] direct observation

If medical and diagnostic information is not available it is suggested to complete appendix 1: Brief Health Information (p 9-10) which can be completed by the respondent.

H 2. Date __ __ /__ __/__ __ ***H 3. Case ID*** _ _ , __ __ __ , __ ***H 4. Participant No.*** __ __ , __ __ , __ __ __
Day Month Year CE or CS Case No. 1st or 2nd Evalu FTC Site Participant

A. DEMOGRAPHIC INFORMATION

A.1 NAME *(optional)* First _____ FAMILY_____

A.2 SEX (1) [ ] Female (2) [ ] Male

A.3 DATE OF BIRTH _ _/_ _/_ _ *(date/month/year)*

A.4 ADDRESS *(optional)*

A.5 YEARS OF FORMAL EDUCATION _ _

A.6 CURRENT MARITAL STATUS: *(Check only one that is most applicable)*

(1) Never married	[ ]	(4) Divorced	[ ]
(2) Currently Married	[ ]	(5) Widowed	[ ]
(3) Separated	[ ]	(6) Cohabiting	[ ]

A.7 CURRENT OCCUPATION *(Select the single best option)*

(1) Paid employment	[ ]	(6) Retired	[ ]
(2) Self-employed	[ ]	(7) Unemployed (health reason)	[ ]
(3) Non-paid work, such as volunteer/charity	[ ]	(8) Unemployed (other reason)	[ ]
(4) Student	[ ]	(9) Other	[ ]
(5) Keeping house/House-maker	[ ]	*(please specify)* _____	

A.8 MEDICAL DIAGNOSIS of existing Main Health Conditions, ***if possible give ICD Codes.***

1. No Medical Condition exists
2. …….. ICD code: __. __. __.__. __
3. …….. ICD code: __. __. __.__. __
4. …….. ICD code: __. __. __.__. __
5. A Health Condition (disease, disorder, injury) exists, however its nature or diagnosis is not known

PART 1a: IMPAIRMENTS of BODY FUNCTIONS

- Body functions are the physiological functions of body systems (including psychological functions).
- Impairments are problems in body function as a significant deviation or loss.

First Qualifier: *Extent of impairments*
0 No impairment means the person has no problem ***1 Mild impairment*** means a problem that is present less than 25% of the time, with an intensity a person can tolerate and which happens rarely over the last 30 days. ***2 Moderate impairment*** means that a problem that is present less than 50% of the time, with an intensity, which is interfering in the persons day to day life and which happens occasionally over the last 30 days. ***3 Severe impairment*** means that a problem that is present more than 50% of the time, with an intensity, which is partially disrupting the persons day to day life and which happens frequently over the last 30 days. ***4 Complete impairment*** means that a problem that is present more than 95% of the time, with an intensity, which is totally disrupting the persons day to day life and which happens every day over the last 30 days. ***8 Not specified*** means there is insufficient information to specify the severity of the impairment. ***9 Not applicable*** means it is inappropriate to apply a particular code (e.g. b650 Menstruation functions for woman in pre-menarche or post-menopause age).

Short List of Body Functions	***Qualifier***
b1. MENTAL FUNCTIONS	
b110 Consciousness	
b114 Orientation *(time, place, person)*	
b117 Intellectual *(incl. Retardation, dementia)*	
b130 Energy and drive functions	
b134 Sleep	
b140 Attention	
b144 Memory	
b152 Emotional functions	
b156 Perceptual functions	
b164 Higher level cognitive functions	
b167 Language	
b2. SENSORY FUNCTIONS AND PAIN	
b210 Seeing	
b230 Hearing	
b235 Vestibular *(incl. Balance functions)*	
b280 Pain	
b3. VOICE AND SPEECH FUNCTIONS	
b310 Voice	
b4. FUNCTIONS OF THE CARDIOVASCULAR, HAEMATOLOGICAL, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS	
b410 Heart	
b420 Blood pressure	
b430 Haematological *(blood)*	
b435 Immunological *(allergies, hypersensitivity)*	
b440 Respiration *(breathing)*	
b5. FUNCTIONS OF THE DIGESTIVE, METABOLIC AND ENDOCRINE SYSTEMS	
b515 Digestive	
b525 Defecation	
b530 Weight maintenance	
b555 Endocrine glands *(hormonal changes)*	
b6. GENITOURINARY AND REPRODUCTIVE FUNCTIONS	
b620 Urination functions	

b640 Sexual functions	
b7. NEUROMUSCULOSKELETAL AND MOVEMENT RELATED FUNCTIONS	
b710 Mobility of joint	
b730 Muscle power	
b735 Muscle tone	
b765 Involuntary movements	
b8. FUNCTIONS OF THE SKIN AND RELATED STRUCTURES	
ANY OTHER BODY FUNCTIONS	

Part 1 b: IMPAIRMENTS of BODY STRUCTURES

- Body structures are anatomical parts of the body such as organs, limbs and their components.
- Impairments are problems in structure as a significant deviation or loss.

First Qualifier: ***Extent of impairment***	**Second Qualifier:** ***Nature of the change***
0 No impairment means the person has no problem ***1 Mild impairment*** means a problem that is present less than 25% of the time, with an intensity a person can tolerate and which happens rarely over the last 30 days. ***2 Moderate impairment*** means that a problem that is present less than 50% of the time, with an intensity, which is interfering in the persons day to day life and which happens occasionally over the last 30 days. ***3 Severe impairment*** means that a problem that is present more than 50% of the time, with an intensity, which is partially disrupting the persons day to day life and which happens frequently over the last 30 days. ***4 Complete impairment*** means that a problem that is present more than 95% of the time, with an intensity, which is totally disrupting the persons day to day life and which happens every day over the last 30 days. ***8 Not specified*** means there is insufficient information to specify the severity of the impairment. ***9 Not applicable*** means it is inappropriate to apply a particular code (e.g. b650 Menstruation functions for woman in pre-menarche or post-menopause age).	**0** No change in structure **1** Total absence **2** Partial absence **3** Additional part **4** Aberrant dimensions **5** Discontinuity **6** Deviating position **7** Qualitative changes in structure, including accumulation of fluid **8** Not specified **9** Not applicable

Short List of Body Structures	**First Qualifier:** ***Extent of impairment***	**Second Qualifier:** ***Nature of the change***
s1. STRUCTURE OF THE NERVOUS SYSTEM		
s110 Brain		
s120 Spinal cord and peripheral nerves		
s2. THE EYE, EAR AND RELATED STRUCTURES		
s3. STRUCTURES INVOLVED IN VOICE AND SPEECH		
s4. STRUCTURE OF THE CARDIOVASCULAR, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS		
s410 Cardiovascular system		
s430 Respiratory system		
s5. STRUCTURES RELATED TO THE DIGESTIVE, METABOLISM AND ENDOCRINE SYSTEMS		

s6. STRUCTURE RELATED TO GENITOURINARY AND REPRODUCTIVE SYSTEM		
s610 Urinary system		
s630 Reproductive system		
s7. STRUCTURE RELATED TO MOVEMENT		
s710 Head and neck region		
s720 Shoulder region		
s730 Upper extremity *(arm, hand)*		
s740 Pelvis		
s750 Lower extremity *(leg, foot)*		
s760 Trunk		
s8. SKIN AND RELATED STRUCTURES		
ANY OTHER BODY STRUCTURES		

PART 2: ACTIVITY LIMITATIONS & PARTICIPATION RESTRICTION

- *Activity is the execution of a task or action by an individual.. Participation is involvement in a life situation.*
- *Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may have in involvement in life situations.*

*The **Performance qualifier** indicates the **extent of Participation restriction** by describing the persons **actual performance** of a task or action **in his or her current environment.** Because the current environment brings in the societal context, performance can also be understood as "involvement in a life situation" or "the lived experience" of people in the actual context in which they live. This context includes the environmental factors – all aspects of the physical, social and attitudinal world that can be coded using the Environmental. The Performance qualifier measures the difficulty the respondent experiences in **doing things, assuming that they want to do them**.*

*The **Capacity qualifier** indicates the **extent of Activity limitation** by describing the **person ability** to execute a task or an action. The Capacity qualifier focuses on limitations that are inherent or intrinsic features of the person themselves. These limitations should be direct manifestations of the respondent's health state, **without the assistance**. By assistance we mean the help of another person, or assistance provided by an adapted or specially designed tool or vehicle, or any form of environmental modification to a room, home, workplace etc.. The level of capacity should be judged relative to that normally expected of the person, or the person's capacity before they acquired their health condition.*

Note: Use Appendix 2 if needed to elicit information on the Activities and Participation of the individual

First Qualifier: *Performance* *Extent of Participation Restriction*	**Second Qualifier:** *Capacity (without assistance)* *Extent of Activity limitation*
0 No difficulty means the person has no problem ***1 Mild difficulty*** means a problem that is present less than 25% of the time, with an intensity a person can tolerate and which happens rarely over the last 30 days. ***2 Moderate difficulty*** means that a problem that is present less than 50% of the time, with an intensity, which is interfering in the persons day to day life and which happens occasionally over the last 30 days. ***3 Severe difficulty*** means that a problem that is present more than 50% of the time, with an intensity, which is partially disrupting the persons day to day life and which happens frequently over the last 30 days. ***4 Complete difficulty*** means that a problem that is present more than 95% of the time, with an intensity, which is totally disrupting the persons day to day life and which happens every day over the last 30 days. ***8 Not specified*** means there is insufficient information to specify the severity of the difficulty. ***9 Not applicable*** means it is inappropriate to apply a particular code (e.g. b650 Menstruation functions for woman in pre-menarche or post-menopause age).	

Short List of A&P domains	*Performance Qualifier*	*Capacity Qualifier*
d1. LEARNING AND APPLYING KNOWLEDGE		
d110 Watching		
d115 Listening		
d140 Learning to read		
d145 Learning to write		
d150 Learning to calculate *(arithmetic)*		
d175 Solving problems		
d2. GENERAL TASKS AND DEMANDS		
d210 Undertaking a single task		
d220 Undertaking multiple tasks		
d3. COMMUNICATION		
d310 Communicating with -- receiving -- spoken messages		
d315 Communicating with -- receiving -- non-verbal messages		
d330 Speaking		
d335 Producing non-verbal messages		
d350 Conversation		
d4. MOBILITY		
d430 Lifting and carrying objects		
d440 Fine hand use *(picking up, grasping)*		
d450 Walking		
d465 Moving around using equipment *(wheelchair, skates, etc.)*		
d470 Using transportation *(car, bus, train, plane, etc.)*		
d475 Driving (riding bicycle and *motorbike, driving car, etc.)*		
d5. SELF CARE		
d510 Washing oneself *(bathing, drying, washing hands, etc)*		
d520 Caring for body parts *(brushing teeth, shaving, grooming, etc.)*		
d530 Toileting		
d540 Dressing		
d550 Eating		
d560 Drinking		
d570 Looking after one`s health		
d6. DOMESTIC LIFE		
d620 Acquisition of goods and services *(shopping, etc.)*		
d630 Preparation of meals *(cooking etc.)*		
d640 Doing housework *(cleaning house, washing dishes laundry, ironing, etc.)*		
d660 Assisting others		
d7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS		
d710 Basic interpersonal interactions		
d720 Complex interpersonal interactions		
d730 Relating with strangers		
d740 Formal relationships		
d750 Informal social relationships		
d760 Family relationships		
d770 Intimate relationships		
d8. MAJOR LIFE AREAS		

d810 Informal education		
d820 School education		
d830 Higher education		
d850 Remunerative employment		
d860 Basic economic transactions		
d870 Economic self-sufficiency		
d9. COMMUNITY, SOCIAL AND CIVIC LIFE		
d910 Community Life		
d920 Recreation and leisure		
d930 Religion and spirituality		
d940 Human rights		
d950 Political life and citizenship		
ANY OTHER ACTIVITY AND PARTICIPATION		

PART 3: ENVIRONMENTAL FACTORS

- *Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.*

Qualifier in environment:	**0** No barriers	**0** No facilitator
Barriers or facilitator	**1** Mild barriers	+**1** Mild facilitator
	2 Moderate barriers	+**2** Moderate facilitator
	3 Severe barriers	+**3** Substantial facilitator
	4 Complete barriers	+**4** Complete facilitator

Short List of Environment	***Qualifier barrier or facilitator***
e1. PRODUCTS AND TECHNOLOGY	
e110 For personal consumption *(food, medicines)*	
e115 For personal use in daily living	
e120 For personal indoor and outdoor mobility and transportation	
e125 Products for communication	
e150 Design, construction and building products and technology of buildings for public use	
e155 Design, construction and building products and technology of buildings for private use	
e2. NATURAL ENVIRONMENT AND HUMAN MADE CHANGES TO ENVIRONMENT	
e225 Climate	
e240 Light	
e250 Sound	
e3. SUPPORT AND RELATIONSHIPS	
e310 Immediate family	
e320 Friends	
e325 Acquaintances, peers, colleagues, neighbours and community members	
e330 People in position of authority	
e340 Personal care providers and personal assistants	
e355 Health professionals	
e360 Health related professionals	
e4. ATTITUDES	
e410 Individual attitudes of immediate family members	
e420 Individual attitudes of friends	
e440 Individual attitudes of personal care providers and personal assistants	
e450 Individual attitudes of health professionals	
e455 Individual attitudes of health related professionals	
e460 Societal attitudes	
e465 Social norms, practices and ideologies	
E5. SERVICES, SYSTEMS AND POLICIES	
e525 Housing services, systems and policies	
e535 Communication services, systems and policies	
e540 Transportation services, systems and policies	
e550 Legal services, systems and policies	
e570 Social security, services, systems and policies	
e575 General social support services, systems and policies	
e580 Health services, systems and policies	
e585 Education and training services, systems and policies	
e590 Labour and employment services, systems and policies	
ANY OTHER ENVIRONMENTAL FACTORS	

Part 4: OTHER CONTEXTUAL INFORMATION

4. 1 *Give a thumbnail sketch of the individual and any other relevant information.*

4.2 *Include any* ***Personal Factors*** *as they impact on functioning (e.g. lifestyle, habits, social background, education, life events, race/ethnicity, sexual orientation and assets of the individual).*

Appendix 1:

BRIEF HEALTH INFORMATION

[ ] Self Report **[ ] Clinician Administered**

X.1 Height : __/__/__ cm *(or inches)*

X.2 Weight: __/__/__ kg *(or pounds)*

X.3 Dominant Hand *(prior to health condition)*: Left [ ] Right [ ] Both hands equally [ ]

X.4 How do you rate your physical health in the past month?

Very good [ ] Good [ ] Moderate [ ] Bad [ ] Very bad [ ]

X.5 How do you rate your mental and emotional health in the past month?

Very good [ ] Good [ ] Moderate [ ] Bad [ ] Very bad [ ]

X.6 Do you currently have any disease(s) or disorder(s) ?

[ ] NO [ ] YES

*If YES, please specify:*_____

_____

X.7 Did you ever have any significant injuries that had an impact on your level of functioning?

[ ] NO [ ] YES

If YES, please specify _____

_____

X.8 Have you been hospitalized in the last year?

[ ] NO [ ] YES

If YES, please specify reason(s) and for how long?

1. _____; ___. ___. ___ days
2. _____; ___. ___. ___ days
3. _____; ___. ___. ___ days

X.9 Are you taking any medication (either prescribed or over the counter)?

[ ] NO [ ] YES

If YES, please specify major medications

1. _____
2. _____
3. _____

X.10 Do you smoke?

[ ] NO [ ] YES

X.11 Do you consume alcohol or drugs?

[ ] NO [ ] YES

If YES, please specify average daily quantity

Tobacco: _____
Alcohol: _____
Drugs: _____

X.12 Do you use any assistive device such as glasses, hearing aid, wheelchair, etc.?

[ ] NO [ ] YES

If YES, please specify

_____

X.13 Do you have any person assisting you with your self care, shopping or other daily activities?

[ ] NO [ ] YES

If YES, please specify person and assistance they provide

_____

X.14 Are you receiving any kind of treatment for your health?

[ ] NO [ ] YES

If YES, please specify:

_____

X.15 Additional significant information on your past and present health:

_____

_____

X.16 IN THE PAST MONTH, have you cut back (i.e. reduced) your usual activities or work because of your *health condition*? (a disease, injury, emotional reasons or alcohol or drug use)

[ ] NO [ ] YES If yes, how many days? _____

X.17 IN THE PAST MONTH, have you been totally unable to carry out your usual activities or work because of your *health condition*? (a disease, injury, emotional reasons or alcohol or drug use)

[ ] NO [ ] YES If yes, how many days? _____

Appendix 2:

GENERAL QUESTIONS FOR PARTICIPATION & ACTIVITIES

The following probes are proposed as a guide to help the examiner when interviewing the respondent about problems in functioning and life activities, in terms of the distinction between capacity and performance Take into account all personal information known about the respondent and ask any additional probes as necessary. Probes should be rephrased as open-ended questions if necessary to elicit greater information.

Under each domain there are two kinds of probes:

*The first probe tries to get the respondent to focus on his or her **capacity** to do a task or action, and in particular to focus on limitations in capacity that are **inherent or intrinsic features of the person** themselves. These limitations should be direct manifestations of the respondent's health state, without the assistance. By **assistance** we mean the help of another person, or assistance provided by an adapted or specially designed tool or vehicle, or any form of environmental modification to a room, home, workplace and so o. The level of capacity should be judged relative to that normally expected of the person, or the person's capacity before they acquired their health condition.*

*The second probe focuses on the respondent's **actual performance** of a task or action in the person's actual situation or surroundings, and elicits information about the effects of environmental barriers or facilitators. It is important to emphasize that you are only interested in the extent of difficulty the respondent has in doing things, **assuming that they want to do them**. Not doing something is irrelevant if the person chooses not to do it.*

I. Mobility

(Capacity)

(1) In your present state of health, how much difficulty do you have walking long distances (such as a kilometer or more) without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "…than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your present surroundings, how much of a problem do you actually have in walking long distances (such as a kilometer or more)?

(2) Is this problem walking made worse, or better, by your actual surroundings?

(3) Is your capacity to walk long distances without assistance more or less than what you actually do in your present surroundings?

II. Self Care

(Capacity)

(1) In your present state of health, how much difficulty do you have washing yourself, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "…than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your own home, how much of a problem do you actually have washing yourself?

(2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?

(3) Is your capacity to wash yourself without assistance more or less than what you actually do in your present surroundings?

III. Domestic Life

(Capacity)

(1) In your present state of health, how much difficulty do you have cleaning the floor of your where you live, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "…than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your own home, how much of a problem do you actually have cleaning the floor?

(2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?

(3) Is your capacity to clean your floor without assistance more or less than what you actually do in your present surroundings?

IV. Interpersonal Interactions

(Capacity)

(1) In your present state of health, how much difficulty do you have making new friends, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "…than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your present situation, how much of a problem do you actually have making friends?

(2) Is this problem making friends made worse, or better, by anything (or anyone) in your surroundings?

(3) Is your capacity to make friends, without assistance, more or less than what you actually do in your present surroundings?

V. Major Life Areas

(Capacity)

(1) In your present state of health, how much difficulty do you have getting done all the work you need to do for your job, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "…than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your present surroundings, how much of a problem do you actually have getting done all the work you need to do for your job?

(2) Is this problem fulfilling your job requirements made worse, or better, by the way the work environment is set up or the specially adapted tools you use?

(3) Is your capacity to do your job, without assistance, more or less than what you actually do in your present surroundings?

VI. Community, Social and Civic Life

(Capacity)

(1) In your present state of health, how much difficulty do you have participating in community gatherings, festivals or other local events, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "…than you had before you developed your health problem or had the accident?)

(Performance)

(1) In your community, how much of a problem do you actually have participating in community gatherings, festivals or other local events?

(2) Is this problem made worse, or better, by the way your community is arranged or the specially adapted tools, vehicles or whatever you use?

(3) Is your capacity to participate in community events, without assistance, more or less than what you actually do in your present surroundings?

Appendix 3:

GUIDELINES FOR THE USE OF ICF CHECKLIST VERSION 2.1A

1. This is a checklist of major categories of International Classification of Functioning, Disability and Health (ICF) of the World Health Organization . The ICF Checklist is a practical tool to elicit and record information on the functioning and disability of an individual. This information can be summarized for case records (for example, in clinical practice or social work).

2. This version (2.1a) is for use by a clinician, health or social care professional.

3. The checklist should be used along with the ICF full or short version which is scheduled for publication in September 2001. Until then the ICIDH-2 Final Draft, full version, WHO, 2001 will serve as reference document for the ICF checklist. The raters should familiarize themselves with the ICIDH-2 Final Draft by attending a brief educational programme or self-taught curriculum.

4. All information from written records, primary respondent, other informants and direct observation can be used to fill in the checklist. Please record all sources of information used on the first page.

5. Parts 1 to 3 should be filled in by writing the qualifier code against each of the function, structure, activity and participation term that shows some problem for the case being evaluated. Appropriate codes for the qualifiers are given on the relevant pages.

6. Comments can be made regarding any information that can serve as the additional qualifier or that is thought to be significant for the case being evaluated.

7. Part 4 (Environment) has both negative (barrier)and positive (facilitator) qualifier codes. For all positive qualifier codes, please use a plus (+) sign before the code.

8. The categories given in the checklist have been selected from the ICF and are not exhaustive. If you need to use a category that you do not find listed here, use the space at the end of each dimension to record these.

APPENDIX 5

SRQ 20

The following questions are related to certain pains and problems, that may have bothered you in the last 30 days. If you think the question applies to you and you the described problem in the last 30 days, answer YES.
On the other hand if the question does not apply to you and you did not have the problem in the last 30 days answer NO.
Please do not discuss the questions with anyone while answering the questionnaire.
If you are unsure about how to answer a question, please give the best answer you can.
We would like to reassure that the answers you are going to provide here are confidential.

1. Do you often have headaches? yes/no
2. Is your appetite poor? * yes/no
3. Do you sleep badly? yes/no
4. Are you easily frightened? yes/no
5. Do your hands shake? * yes/no
6. Do you feel nervous, tense or worried? yes/no
7. Is your digestion poor? * yes/no
8. Do you have trouble thinking clearly? yes/no
9. Do you feel unhappy? * yes/no
10. Do you cry more than usual? yes/no
11. Do you find it difficult to enjoy your daily activities? yes/no
12. Do you find it difficult to make decisions? * yes/no
13. Is your daily work suffering? yes/no
14. Are you unable to play a useful part in life? * yes/no
15. Have you lost interest in things? yes/no
16. Do you feel that you are a worthless person? * yes/no
17. Has the thought of ending your life been on your mind? yes/no
18. Do you feel tired all the time? * yes/no
19. Do you have uncomfortable feelings in your stomach?* yes/no
20. Are you easily tired? * yes/no

The Infant Gross Motor Screening Test

Instructions for use

Purpose

The Infant Gross Motor Screening Test was developed to assess the gross motor function of HIV positive Infants between the ages of 6 and 18 months.

User Qualifications

The Infant Gross Motor Screening Test was designed to be used by those working in a paediatric HIV setting, and does not require profession specific training. Potential users should be trained in the administration of the items, and the observation of responses from the child.

Administration time

The Infant Gross Motor Screening Test takes 5 - 10 minutes to administer.

Administration procedure

- The child's exact age in months should be calculated, and correction for prematurity should be made.
- The correct age group should be selected from the test score sheet
- Items should be administered in a quiet child-friendly environment. The child's caregiver may be used to place the child in the necessary position should the child be upset by the administrator handling him/her
- Items do not need to be administered in sequential order, but responses need to be observed in order to be credited, the administrator may not give credit based on parent-report.
- All items should be completed for the age group

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Scoring

- For each item that the child achieves, a score of ‘1’ should be given
- If the child does not achieve the item, a score of ‘0’ should be given
- Once all the items have been completed, the child’s total score should be obtained by adding up the ‘1’s and ‘0’s.
- The child’s corresponding developmental category can be found at the bottom of the page.

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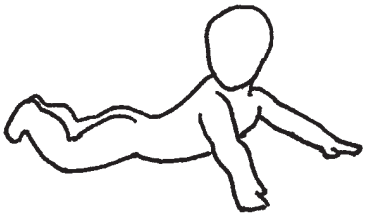
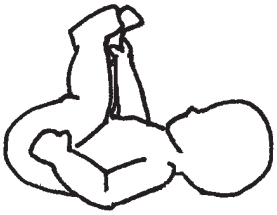
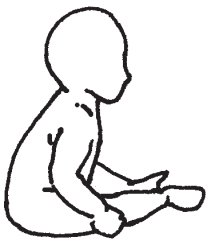
The Infant Gross Motor Screening Test 6-8 months

Date of Assessment____/____/_____

Child's name_____

Date of Birth____/____/_____

Age_____ months

		Score
	**Controls head at 90 degrees while lying on stomach** Child lies on stomach, and should be able to lift head up to 90 degrees for about 5 seconds	☐
	**Elevates chest whilst lying on stomach (with extended arms)** Child supports weight on both hands, whilst keeping arms straight, and lifting head at 90 degrees	☐
	**Plays with feet** Child should bring one or both feet to hands (above the hips), and be able to maintain this position whilst playing with feet	☐
	**Rolls from back to stomach** Child can do this to both or one side. This should be voluntary, and initiated by lifting the head	☐
	**Sits alone** The child should be able to sit alone for about 30 seconds without using arms for support	☐

6-7 months	8 months
☐ 4-5 Satisfactory	☐ 5 Satisfactory
☐ 0-3 At risk	☐ 0-4 At risk

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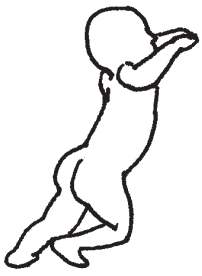
The Infant Gross Motor Screening Test 9-12 months

Child's name_____

Date of Birth____/____/_____

Date of Assessment____/____/_____

Age_____ months

		Score
	**Turns body while seated** Child turns his or her trunk and reaches for object	☐
	**Makes stepping movements** Child makes at least two stepping movements that move him/herself forward whilst hands are held	☐
	**Moves from sitting to being on hands and knees** Child uses rotation to move from sitting to being on hands and knees	☐
	**Crawls/moves forward at least 1½ metres** Child uses crawling/moving on stomach and pulling with hands to move forwards at least 1 ½ metres	☐
	**Pulls up to standing position** Child uses an object such as a table in order to pull him/herself into a standing position, or pushes up on the floor without support	☐

9-10 months	11-12 months
☐ 4-5 Satisfactory	☐ 5 Satisfactory
☐ 0-3 At risk	☐ 0-4 At risk

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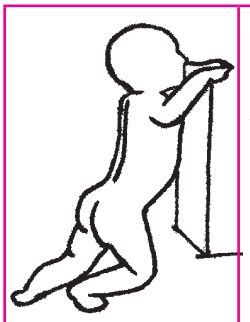
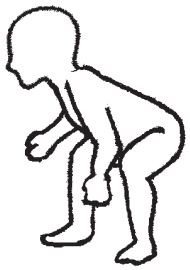
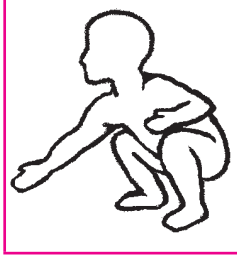
The Infant Gross Motor Screening Test 13-16 months

Child's name_____

Date of Birth____/____/_____

Date of Assessment____/____/_____

Age_____ months

		Score
	**Pulls up to standing position** Child uses an object such as a table in order to pull him/herself into a standing position, or pushes up on the floor without support	☐
	**Sits down from supported standing in a controlled manner** Child sits down from a standing position using good control e.g. by using a controlled squat	☐
	**Stands independently** Child is able to stand without support for at least 20 seconds	☐
	**Walks alone with coordination** Child should be able to walk a reasonable distance (such as 20 steps) with good control and coordination	☐
	**Squats without support** The child should be able to squat down with good control, and maintain this position for play. The child's bottom should not be resting on the floor	☐

13 months	14 months	15-16 months
☐ 3-5 Satisfactory	☐ 4-5 Satisfactory	☐ 5 Satisfactory
☐ 0-2 At risk	☐ 0-3 At risk	☐ 0-4 At risk

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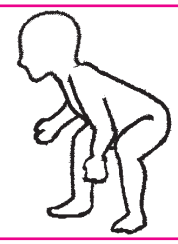
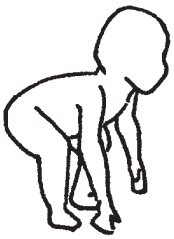
The Infant Gross Motor Screening Test 17-18 months

Child's name_____

Date of Birth____/____/_____

Date of Assessment____/____/_____

Age_____ months

		Score
	**Sits down from supported standing in a controlled manner** Child sits down from a standing position using good control e.g. by using a controlled squat	☐
	**Stands independently** Child is able to stand without support for at least 1 minute	☐
	**Stands up with no assistance** Child moves into a standing position without using an object to pull on. The child may push up on the floor in order to stand up	☐
	**Walks alone with coordination** Child should be able to walk a reasonable distance (such as 40 steps) with good control and coordination	☐
	**Squats without support** The child should be able to squat down with good control, and maintain this position for play. The child's bottom should not be resting on the floor	☐
	**Runs with coordination** The child should be able to run without falling over	☐

17-18 months

☐ 6 Satisfactory

☐ 0-5 At risk

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Appendix 7 Neuropathy Diagnostic Tool

Name of person administering tool: _____

What is your position at FACES?

- ❑ Community Health Worker
- ❑ Clinic Community Health Assistant
- ❑ Nurse
- ❑ Clinical Officer
- ❑ Medical Officer
- ❑ Other, please specify _____

HIV NEUROPATHY DIAGNOSTIC TOOL

PART A

Please ask the patient to rate the **current** severity of each of the following symptoms on a scale of 1 (mild) to 10 (most severe). Use 0 if the symptom is not present.

	Right (0 – 10)	**Left (0-10)**
Pain, aching or burning in the feet or legs		
"Pins and needles" in feet or legs		
Numbness (lack of feeling in the feet or legs)		

IF all of the above are 0, skip to Part C

PART B

Does the numbness, pain, burning or tingling in your legs limit you in these activities? If so, how much? (Tick the appropriate box.)

	Yes, limited a lot	**Yes, limited a little**	**No, not limited at all**
Vigorous activities, such as lifting heavy objects, participating in football, farming, washing clothes by hand, carrying water			
Moderate activities, such as moving a table, light household chores, riding a bicycle, walking			
Climbing one flight of stairs or a small hill			
Walking 50 meters (1/2 a football pitch)			

PART C

Please check the patient's ankle reflexes (i.e. ankle jerks).

0 = absent 1 = decreased 2 = normal 3 = increased 4 = clonus

	Right (0 – 4)	**Left (0 – 4)**
Ankle reflexes		

Communication forALL: You can tell and be heard

how kanjani	burn shisa	get thola	sad hurt feelings Ngi dabukile	in nga phakath	family umndeni	night e busuku
what ini	don't unga	know azana	angry thukuthele	out phandle	home e khaya	food ukudla
when nini	help siza	look bheka	forced isicindezelo	under nga phansi	I/me/mine mina	gun isibhamo
where kuphi	please/beg ngi ya cela	sex uku - lalana	scared thukile	man/him/he indoda	police iphoyisa	money/sweets imali/ amaswiti
who ubani	stop ima	shout/scream ukukhala	alone ngedwa	sore ku buhlungu	toilet bathroom indlu yangasese	mother u - mama
they bona	tell tshela xoxa	steal tjontja	ashamed shy amahloni	woman she/her umfazi	alcohol utjwala	secret imfihlo
not on this board hayi leli bhoti	touch bamba	swear thuka	bad e-ngalungile	clothes izingubo	car imoto	school work umsebenziwe sikole
hit/punch shaya	bleed igazi	threaten beka e ngozini	friendly azana	doctor dokotela	day emini ilang	father u baba

I can't speak, but can hear and understand you.
A ngi kwazi u ku khuluma, kodwa ngi yeswa.
Futhi ngi ya zwisisa

Please contact my family.

Biza abazali bami

Ask me questions if you need to, but please wait patiently for my answers

Ngi buze umbozo, bekezela ngi za ku phendula

I will point where...

Ngiza ku khomba la ku bhuhlungu khona