

# HIV, disability and rehabilitation

Darren Brown

Specialist HIV Physiotherapist, Chelsea and Westminster Hospital NHS Foundation Trust,  
London, UK

## Abstract

With effective treatments, people living with HIV can now have normal life expectancies, grow older, and live with concurrent health conditions. Consequently, many people living and ageing with HIV now face new or worsening experiences of a wide variety of disability. The conceptualisation of disability is complex and has evolved over time. Disability can be broadly defined as any physical, cognitive, mental or emotional impairment, difficulty with day-to-day activities, challenges to social inclusion, or uncertainty, which can be episodic in nature. A range of measurement tools are available to evaluate the nature and extent of disability. The HIV Disability Questionnaire is the sole HIV-specific disability measurement tool. Identification of people at risk of, or experiencing disability, enables access to the right services at the right time. Rehabilitation is a fundamental health service and is the care needed when a person is experiencing, or likely to experience, limitations in everyday functioning or disability. Evidence-informed recommendations for HIV rehabilitation guide best practice and can inform person-centred HIV health care.

**Keywords:** HIV, functioning, disability, rehabilitation

## A. Revalidation

This article has been prepared with continuing professional development (CPD) in mind and can be used to support your revalidation. It is estimated that 2.5 hours of CPD activity will be required for completion of the reading, 'time out' activities, the quiz and writing a brief reflective account in relation to your learning and its applicability to your practice. There is a self-assessment quiz at the end of this article for you to assess what you have learnt.

## B. Aims and intended learning outcomes

This article firstly aims to increase your knowledge of functioning, disability and rehabilitation specific to people living and ageing with HIV. Secondly, this article aims to develop your skills in screening, measuring and addressing disability experienced by people living with HIV.

After reading this article, undertaking the activities and completing the self-assessment quiz you should be able to:

- understand and define functioning, disability and rehabilitation;
- understand and define frameworks of disability specific to people living with HIV;
- describe how to screen and measure disability among people living with HIV;
- outline the role of multidisciplinary rehabilitation in the context of people living with HIV who experience disability;
- show awareness of the nurse's role within HIV rehabilitation; and
- review your current practice and develop disability-inclusive approaches in caring for people living and ageing with HIV.

## C. Introduction

For the 37.9 million people living with HIV globally [1], universal access to antiretroviral therapies (ART) offers normal life expectancy [2], with 24.5 million people accessing ART in 2019 [1]. With access to effective and tolerable ART, the numbers of people living with HIV aged  $\geq 50$  years are increasing at exponential and unprecedented rates [3]. As people live longer with chronic HIV they may be susceptible to health conditions caused by the underlying HIV condition, potential side effects of treatments, and ageing [4]. Consequently multimorbidity among people living and ageing with HIV is increasingly prevalent [5]. Common concurrent health conditions include cardiovascular disease [6], diabetes [7], bone and joint disorders [8,9], neurocognitive disorders [10,11], chronic pain [12], mental health conditions [13], cancer [14], and frailty [15]. People living with HIV can also experience additional challenges of stigma, ageism, income insecurity, and lack of social support, which may impact or intersect with issues of living and ageing with HIV [16–19]. Collectively these challenges may be conceptualised as 'disability' [20]. Many people living and ageing with HIV on long-term ART, now face new or worsening experiences of a wide variety of disability [4,21]. Disability experienced by people living with HIV is now increasingly recognised as an important, yet underexplored area [22,23].

### Time out activity 1

Before reading the rest of this article, write down your understanding of disability.

Upon completion of reading this article, write down whether your understanding of disability has been confirmed, modified or changed. This will support your CPD reflective account.

## D. Defining disability

The conceptualisation of disability is complex and has evolved over time [24]. Initially, disability was viewed within the medical model as a phenomenon determined by impairments of body structure or function [25]. This remains a common approach to thinking about disability, in which disability is viewed as a problem that exists in a person's body [26]. This model implies that the person with functional limitations (impairments) requires treatment or care to fix the disability and does not consider contributing environmental and social factors [27,28]. This medical model has been perceived as 'outdated and oppressive' [29].

Understanding of disability then shifted towards the social model that framed disability as resulting from barriers imposed by societies (e.g. inaccessible built environments, information communication) that isolate and exclude people with impairments from full and equal participation [30]. The social model emphasised that exclusion is the real problem, caused by a social failure to make proper inclusive arrangements rather than by individual biological dysfunctions [29,31]. The social model has been criticised for creating a dichotomy between impairments and disability, which may exclude dimensions of lives of people with disability, such as impairments [32].

The subsequent predominating framework of disability, the *International Classification of Functioning, Disability and Health* (ICF) (Figure 1), combines elements of both medical and social models leading to a 'bio-psycho-social' framework [33]. The ICF describes functioning and disability as multidimensional and the outcome of interactions between a person's health condition(s) and context (environmental and personal factors), involving one or more dysfunctions at the level of impairments, activity limitations and participation restrictions [33]. An impairment is a problem in body function of structure. An activity limitation is a difficulty encountered by an individual in executing a task or action. A participation restriction is a problem experienced by an individual in involvement in life situations.

The purpose of the ICF is to provide a globally agreed, common language and framework for describing functional status in order to allow for comparisons [34]. The ICF is not specific to any health condition, and may not accurately capture the complexity of HIV, the day-to-day health-related consequences of HIV, and their significance from the perspective of people living with HIV [20].

The *Episodic Disability Framework* (EDF) [20] presents a new way to conceptualise disability based on the experience of people living with HIV. The EDF conceptualises disability as multidimensional and episodic, characterised by unpredictable periods of wellness and illness, see Figure 2 [20]. Dimensions of disability described by people living with HIV include any of the following:

1. physical symptoms and impairments;
2. cognitive symptoms and impairments;
3. mental or emotional symptoms and impairments;
4. difficulties with day-to-day activities;
5. challenges to social inclusion; and
6. uncertainty or worry about the future [20].

Similar to the ICF, the EDF highlights how environmental and personal factors including extrinsic factors (e.g. level of social support and stigma) and intrinsic factors (e.g. living strategies, age, and personal attributes) may exacerbate or alleviate each dimension of disability [35,36]. The EDF describes the health-related consequences of HIV, adverse effects of treatments, and concurrent health conditions, which may fluctuate over time. The novel contributions of the EDF are identifying 'uncertainty' or worrying about the future as a key dimension of disability, plus the episodic nature of disability over time.

Defining disability is complex, with a range of available definitions, frameworks and conceptualisations. Disability can however be broadly defined as any physical, cognitive, mental or emotional, and social health challenges that can be experienced as episodic in nature with periods of fluctuating health [20,37]. Understanding a history of disability allows us to

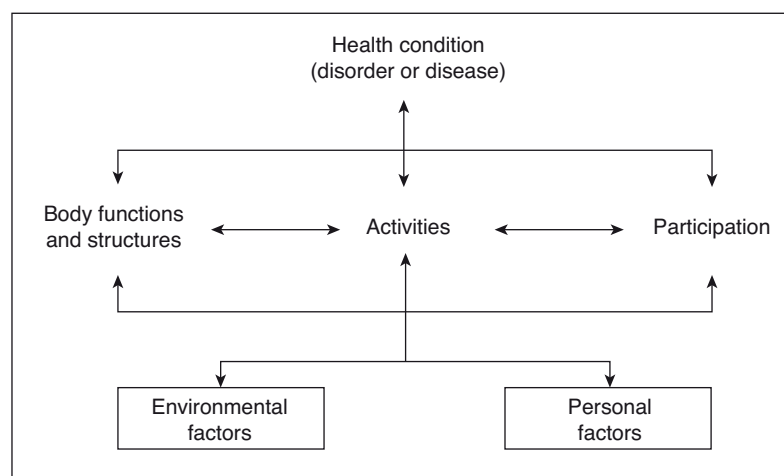


Figure 1: The International Classification of Functioning, Disability and Health (ICF). Reproduced from *How to use the ICF: a practical manual for using the international classification of functioning, disability and health*. Exposure draft for comment. Geneva: World Health Organization, October 2013, p5 [33].

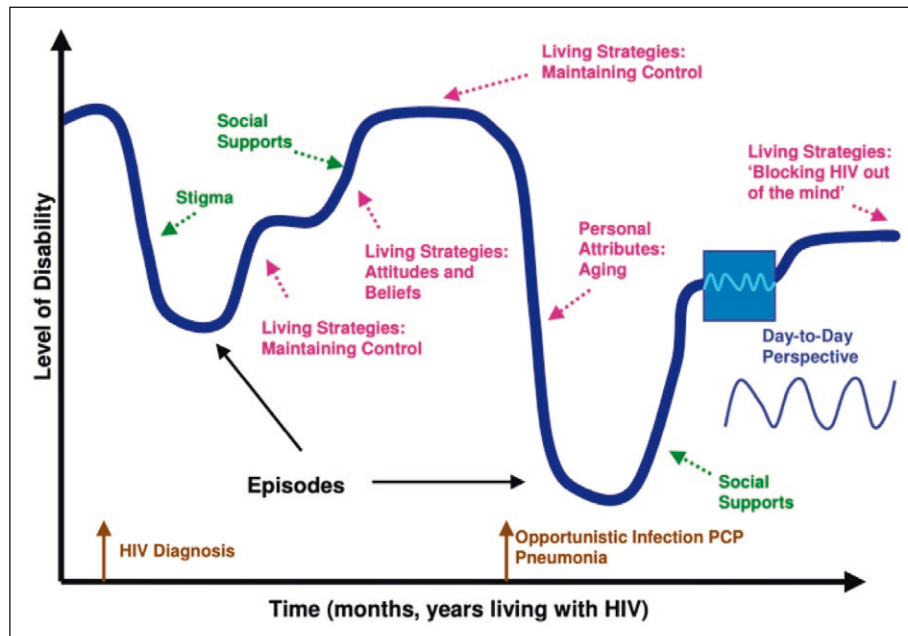


Figure 2: The Episodic Disability Framework (EDF). Source O'Brien et al. *Health Qual Life Outcomes* 2008; 6: 76 [20]. Reproduced without adaptation by kind author permission under CC BY 2.0.

#### Box 1. Definitions of health, quality of life, functioning, disability and rehabilitation

<b>Health</b>	A state of complete physical, mental, and social wellbeing, not merely the absence of disease or infirmity [39].
<b>Quality of life</b>	An individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns [40].
<b>Functioning</b>	The ability of a person to perform everyday activities such as thinking, seeing, hearing, communicating, moving around, having relationships, keeping a job, and participating in social and community roles [41,42].
<b>Disability</b>	Any physical, cognitive, mental or emotional impairments, difficulty with day-to-day activities, challenges to social inclusion, or uncertainty that can be episodic in nature. Disability reflects the interaction between features of a person's body, and the society in which they live [20,41].
<b>Rehabilitation</b>	A fundamental health service that reduces disability and optimises functioning in individuals with health conditions, so as to enable them to better interact with their environment. Rehabilitation is about health and functioning in everyday life [42,43].

appreciate that disability has been defined as multi-dimensional, episodic, and the outcome of a person's body, environment, and society. It is distinct but related to other concepts such as health and quality of life (Box 1). Fundamentally, disability is a universal human experience, where everybody can be placed on a continuum of functioning from no disability (full functioning) to complete disability, and, either currently experiencing, or vulnerable to experiencing, disability over the course of life [38].

#### Time out activity 2

##### Defining disability

With reference to the *Episodic Disability Framework* (EDF), write down the six dimensions of disability.

Think about a patient and write down the disability they may have experienced across any of the six dimensions of disability.

Then write down what contextual factors may exacerbate or alleviate the disability experienced.

## E. Measuring disability

Measuring disability poses several challenges, as there are a wide range of definitions and tools that may be used. Measurement approaches may vary based on the purposes of data collection, including data about impairments, activity limitations, and participation restrictions of interest [25,44,45]. Impairments alone are not an adequate proxy for disability, since people with the same impairment can experience different types and degrees of restriction [44]. Measuring disability based broadly within the ICF, capturing multiple dimensions of disability, is crucial for appropriate service-planning and evidence-based advocacy [24]. The importance of this approach is magnified by the concept of functioning (and consequently decrements in functioning or disability) as the World Health Organization's (WHO's) third health indicator, along with morbidity and mortality, for monitoring performance of health systems and strategies [46].

Tools have been developed to standardise disability measurement, based broadly within the ICF or EDF.

These include the Washington Group on Disability Statistics [47], UK Equality Act disability definition [48], World Health Organization Disability Assessment Schedule 2.0 (WHODAS) [49], Model Disability Survey [38], and HIV Disability Questionnaire (HDQ) [50].

The Washington Group on Disability Statistics developed a short and extended set of questions [47,51] suitable for censuses and national surveys (questions available at: [www.washingtongroup-disability.com](http://www.washingtongroup-disability.com)), to provide basic necessary information on disability that is comparable throughout the world. The Washington Group short set of questions are recommended by the United Nations to measure disability, enabling disaggregation of the Sustainable Development Goals by disability status [52]. They are not to be used in isolation and should be included in larger surveys alongside other measures, such as employment status and educational attainment. The brevity of the tools mean they can be rapidly and easily deployed in a variety of settings to screen for disability, and measure prevalence of disability in a population. The Washington Group short set is the most commonly used version, comprising six core domains of functioning: seeing, hearing, walking, concentrating, self-care, and communicating.

In the UK, national census data on disability is measured on the presence of long-lasting health conditions and illness, plus activity restrictions as classified within the UK Equality Act disability definition (UK Equality Act definition questions can be accessed at: [gss.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/](http://gss.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/)) [48,53]. Two questions designed to harmonise collection of data across UK censuses and surveys ensure UK statistics about disability are comparable:

- Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?
- Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry out day-to-day activities?

Answering 'Yes' to both questions classifies a person as 'disabled'. This approach is brief and can be deployed to screen for disability and measure prevalence. Using the Equality Act disability definition, prevalence of disability among the UK general population and people living with HIV in London UK, is estimated to be 21% [54] and 40% [55] respectively. The Equality Act disability definition and Washington Group questions are both based on similar concepts of disability. Comparison of the different approaches identifies substantially different, although overlapping, groups as disabled and a range of different estimates of disability prevalence [56]. Neither approach is inherently better than the other, however the Equality Act disability definition remains essential to meet the needs of government policy and equalities monitoring, therefore is a priority for Great Britain official statistics [56]. For the purpose of international comparison, it might be possible to estimate Washington Group

questions' disability prevalence from the Equality Act disability definition, however further testing is needed [56]. Cross-European comparisons are already possible with the corresponding global activity limitation indicator (GALI) question in European surveys [56].

The WHO produced the World Health Organization Disability Assessment Schedule 2.0 (WHODAS) as a generic instrument to measure and assess disability and health status, on a continuum or scale from 'no disability' to 'full disability' [49] (available at: [www.who.int/classifications/icf/whodasii/en/](http://www.who.int/classifications/icf/whodasii/en/)). It can be used across all diseases including physical and mental health conditions, and challenges with alcohol or drug use. It is applicable across cultures in adult populations, and directly linked to the ICF framework. It measures six disability dimensions (cognition, mobility, self-care, getting along, life activities and participation), is available in long (36-item) and short (12-item) forms, and can be self-, proxy- or interviewer-administered. Administration is short, simple and easy, taking 5 to 20 minutes. The WHODAS provides 'simple' and 'complex' sum scores. In 'simple' scoring, the scores assigned to each item are summed. In 'complex' scoring, multiple levels of difficulty are factored for each item, providing a score ranging 0–100; where 0 means 'no disability' and 100 means 'full disability'. The WHODAS long and short-forms have been used among people living with HIV in high- [55, 57–59], low-, and middle-income countries [57,60–62]. Continuums of disability can be partitioned by a threshold identified as fit for purpose, including, for example, advocacy for policy change [38]. For the purpose of disability statistics, categorisation thresholds have been developed based on WHODAS scores, to identify people living with HIV experiencing 'disability' (score  $\geq 2$ , representing at least two mild/moderate or one moderate/severe limitation) [55,61,63], and any level of 'functional limitation' (score  $\geq 1$ , representing at least one mild/moderate limitation) [57]. These thresholds permit reporting of 'disability' and 'functional limitation' prevalence rates among people living with HIV in South Africa [57,61,63], US [57] and UK [55].

More recently, WHO produced the Model Disability Survey as a general population survey that provides detailed and nuanced information about how people with and without disabilities conduct their lives and the difficulties they may encounter, regardless of any underlying health condition or impairment [64] (available at: [www.who.int/disabilities/data/mds/en/](http://www.who.int/disabilities/data/mds/en/)). The development of this tool is grounded in the choice to evolve beyond data collection defining a population of individuals who are labelled as 'disabled'. This tool asks people what they do, or do not do, in their daily lives, therefore is concerned with how people function in multiple dimensions given the environmental barriers and facilitators that constitute their real life situations. The Model Disability Survey collects data on all dimensions of disability: impairments, activity limitations, participation restrictions, and the environmental factors that facilitate or hinder full participation [64].

The HIV Disability Questionnaire (HDQ) is the sole HIV-specific patient reported outcome measure of



disability (questions available at: [research.mcmaster.ca/industry-and-investors/hiv-disability-questionnaire-hdq/](http://research.mcmaster.ca/industry-and-investors/hiv-disability-questionnaire-hdq/)) [65]. The 69-item self-administered version (10.5, 2017) is derived from the EDF and developed through a community–academic partnership [50]. The HDQ measures and describes the presence, severity and episodic nature of disability experienced by people living with HIV, on a continuum or scale. It comprises all six disability dimensions within the EDF, as outlined in section D, and also one ‘good or bad day’ health classification item. Participants are asked to rate the level of presence and severity of each health challenge on a given day ranging from 0 (not at all) to 4 (extreme). HDQ scores range on scale from 0 to 100, with higher scores indicating a greater presence, severity and episodic nature of disability. The HDQ has demonstrated sensibility, validity, internal consistency reliability, test-retest reliability, and precision of measurement among people living with HIV in Canada, Ireland, US, and UK [59,66–69]. A short form HDQ is currently under development to facilitate use in clinical and community-based practice. The HDQ should not be used in isolation. It should be administered in combination with other health status instruments that capture extrinsic contextual factors (e.g. social support, stigma) and intrinsic contextual factors (e.g. concurrent health conditions) that can influence disability, to provide a better understanding of the context in which disability is experienced by people living with HIV [50,69]. The disability dimension of ‘uncertainty’ is reported as the most present and severe domain of disability experienced by people living with HIV in Canada, Ireland, US and UK [59,67–69].

Every clinician should appreciate that their patients will experience health in terms of how it impacts on their daily life, in the context of the environment and society in which they live [38]. The diagnosis of signs and symptoms are essential tools, but what often matters most to patients is what they can, or cannot do, in their daily life [38]. This is all the more relevant when people living with HIV are increasingly living with other health conditions, which are likely to be chronic and long lasting. If disability is a universal human experience, where everybody can be positioned onto the continuum of functioning and either currently experiencing or vulnerable to experiencing disability, then disability is about all of us [38]. Measuring disability is indispensable to all of us and must be included in the care of people living with HIV.

### Time out activity 3

#### Measuring disability

Thinking about your clinical practice environment, what measurement tool could you use to screen for disability? What is the purpose of this tool and why would this tool be suitable for the environment in which you practice?

If you identify a patient living with HIV experiencing disability, what measurement tool could you use to measure disability on a continuum or scale? What is the purpose of this tool and why would this tool be suitable for the environment in which you practice?

## F. Rehabilitation

Rehabilitation is a fundamental health service for people with a wide range of health conditions, throughout all stages of life, and during any phase of acute, sub-acute and long-term care [70]. It is the care needed when a person is experiencing, or likely to experience, limitations in everyday functioning or disability [43]. Rehabilitation addresses the impact of health conditions on a person’s life by improving functioning and reducing the experience of disability. Rehabilitation focuses on an individual’s functioning and not the disease. It does this through a strong emphasis on educating and empowering people to manage their health conditions, adapt to their situations and remain as independent as possible. By doing this, rehabilitation enables greater participation in education, employment and community life, with far-reaching health, social and economic benefits [70].

Rehabilitation is a WHO global health priority and key health strategy for the 21st century [71–73], however the need for rehabilitation greatly exceeds its availability [74]. Access to rehabilitation services is critical for people with chronic health conditions, to maintain or enhance independence, participate in communities, improve economic productivity, and enhance quality of life.

With access to ART, people living longer with HIV, prevalent multimorbidity and people living with HIV experiencing disability, it is critical for clinicians, researchers and policy makers to better address disability and incorporate rehabilitation [37,75,76]. Furthermore, rehabilitation is well positioned to address the fourth ‘90’ [37] of UNAIDS global target ‘90-90-90-90’ whereby: 90% of people are aware of their HIV status, 90% of those aware have initiated treatment, 90% of those on treatment achieve viral suppression, and 90% of those undetectable have good mental wellbeing [77–79]. Rehabilitation is well positioned as it is a dynamic process involving prevention, treatment and services that address symptoms, functional limitations and social participation restrictions [75,37].

Traditionally, rehabilitation is delivered by physiotherapy, occupational therapy, speech and language therapy, prosthetics and orthotics, psychology, social work, plus physical and rehabilitation medicine [44]. A multidisciplinary workforce ensures a range of rehabilitation needs, for different domains of functioning and dimensions of disability, can be met [72]. Multidisciplinary rehabilitation may not always be necessary, but it has been shown to be effective in management of chronic, complex or severe health conditions [72]. Nursing adds value to rehabilitation [80] employing education and supportive strategies based on rehabilitation philosophy, goals and concepts to optimise functioning [81]. In the context of HIV, the role of nursing in complex care and care coordination [82] is ideally positioned to measure and address the multidimensional and episodic nature of disability experienced by people living with HIV. Adopting a rehabilitation lens to HIV care, through measuring and addressing functional

limitations or disability, incorporates person-centred and goal-oriented approaches to health promotion and disability prevention [83]. Annual health reviews for people living with HIV are inclusive of physical, cognitive, mental or emotional and social health-related challenges [84]. The annual health review could include measurement of functioning and disability, to identify need, address disability, optimise functioning and facilitate onward referral to rehabilitation services. This approach might prove essential considering the level of unmet need among people living with HIV in the UK [85].

Evidence-informed recommendations for rehabilitation among people living and ageing with HIV include [76]: (1) address comorbidities that may result in physical, cognitive, mental and social health challenges; (2) adopt individualised and interprofessional practice sensitive to the unique needs of people living with HIV, considering intersections between personal and social determinants of health; (3) multidisciplinary rehabilitation, including physiotherapy, occupational therapy plus speech and language therapy, strongly recommended to address multidimensional and episodic disability; (4) consider extrinsic contextual factors e.g. stigma or ageism; (5) consider intrinsic contextual factors e.g. self-management and spirituality; (6) aerobic and resistive exercises are recommended, tailored to individual goals and capacity; (7) cognitive rehabilitation interventions may be recommended; and (8) refer to existing clinical practice guidelines and evidence specific to comorbidities associated with people living with HIV. Exercise as a rehabilitation intervention has strong evidence [86,87], and all nurses in HIV care have an opportunity to help people living with HIV increase their physical activity [88]. Evidence-informed practical recommendations for increasing physical activity among people living with HIV [89] are available to support clinicians to identify barriers, support behaviour change, and support identification of who would most benefit from rehabilitation services. The invaluable role of nursing in identifying need and signposting, to enable people living with HIV to access rehabilitation services, is essential in delivering these rehabilitation recommendations.

Rehabilitation such as physiotherapy can address the complex, episodic nature of disability associated with living with HIV and multimorbidity [75,76], utilising multidimensional and person-centred frameworks [90]. The UK is among the leaders in the field of HIV rehabilitation with more established HIV rehabilitation service delivery across the continuum of care [91,92], plus 'exemplar' service delivery models such as the Kobler Rehabilitation Class ([www.chelwest.nhs.uk/services/therapy-services/hiv-rehabilitation/kobler-rehabilitation-class](http://www.chelwest.nhs.uk/services/therapy-services/hiv-rehabilitation/kobler-rehabilitation-class)) [83,92]. This model provides multidisciplinary rehabilitation including exercise and education to address the multidimensional and episodic nature of disability. The educational self-management programme is delivered by a multidisciplinary workforce including physiotherapists, occupational therapists, psychologists, nurses, dieticians, medical practitioners, health

advisors and community services. It is uniquely open access, meaning people living with HIV can attend, return or restart depending on episodes of wellness, illness or disability. However, HIV rehabilitation services designed to meet the needs of people living with HIV are not universal, and few people living with HIV access formal rehabilitation services [93]. It is vital that people living with HIV experiencing disability access the right rehabilitation service at the right time, such as musculoskeletal physiotherapy, pulmonary rehabilitation, cardiac rehabilitation, falls prevention services, pain management programmes, neuro-rehabilitation, community or home-based rehabilitation and HIV rehabilitation. Knowledge about availability of and access to local rehabilitation services ensures the rehabilitation needs of people living with HIV are inclusive within all HIV services. In the absence of local HIV rehabilitation services, knowledge of available local rehabilitation services advances disability inclusive HIV care.

## G. Disability inclusion

Providing disability inclusive health care, ensures better health for people with disability. Globally, it is estimated that >1 billion people (15% of the world's population) have a disability [44]. Disability is a global health issue because people with disability, throughout the life course, face widespread barriers in accessing health and related services, such as rehabilitation, and have worse health outcomes than people without disability [94]. People with disability face widespread barriers in accessing services, such as health care (including medical care, therapy and assistive technologies), education, employment, and social services (including housing and transport) [94]. The Sustainable Development Goals feature a strong will to 'leave no one behind' including people with disability [95]. The United Nations Convention on the Rights of Persons with Disabilities calls on state parties to ensure the rights of people with disability to participate and be included in all spheres of life, including health and rehabilitation services [96]. However, people with disability have been excluded and neglected in all of the sectors responding to HIV [97]. Disability inclusion was finally integrated into the political Declaration of HIV and AIDS in 2016 [98]. To reach the '90-90-90-90' target requires zero discrimination, person-centred responses, equal access to health programmes and services, including sexual and reproductive health and rights, and integration of rehabilitation into HIV care to enhance quality of life [97,99]. Without improving access to prevention, treatment and chronic care, the obligations of the ambitious UNAIDS Fast-Track Strategy ('90-90-90-90' target) will not reach people with or at risk of disability [99]. Box 2 shows disability-inclusive approaches to HIV care.

## H. Conclusion

People living and ageing with HIV can experience multidimensional and episodic disability. There are a range of screening and measurement tools available

**Box 2. Disability-inclusive approaches to HIV care**

1. Awareness of disability. Being able to define disability, acquire knowledge on measuring disability, and awareness of rehabilitation approaches to address disability experienced by people living with HIV, can be the first principle to demonstrate inclusion of people with disability in HIV care. This requires knowledge translation and exchange, education and skills development plus awareness of resources. This can be achieved through formal education, peer learning, and self-directed study. The evidence-informed e-module for HIV rehabilitation provides a valuable learning resource, and can be accessed on the following link: [www.realizecanada.org/en/resources/e-module/](http://www.realizecanada.org/en/resources/e-module/).
2. Comprehensive accessibility. People with disability are often at higher risk of exposure to HIV, and often do not have equal access to HIV information, education and prevention services [97,100]. Across the continuum of HIV prevention and long-term care, sexual health and HIV, services must be accessible for people with disability, through addressing physical, communication, policy and attitudinal barriers [100]. For example, physical accessibility adjustments for mobility impairments, accessible information resources for people with visual and hearing impairments, or environmental considerations for people who are neuro diverse. The rapid implementation of telehealth owing to the recent COVID-19 pandemic may be beneficial for people with disability in accessing the resources required to participate [101,102]. But our efforts and innovations should not inadvertently increase health inequalities. Simplified tools such as a disability audit of services can help to identify and address issues of accessibility [97,103].
3. Integrate disability screening and measurement into routine care. Disability screening and measurement is not included in routine HIV care or best practice guidelines [104]. The identification of disability is the first step to linking people to the right care at the right time, plus data on disability within HIV services will be crucial to inform disability-inclusive programming [97]. The measurement tools discussed in this article, can be implemented into routine HIV care across a range of clinical practice settings through active engagement from health care, research, policy and political leadership.
4. Find the gaps and generate evidence. 'If you are not counted, you don't count' [105]. The need to improve routine data collection and focused research on disability among people living with HIV is widely reported [99]. National HIV surveys are rarely disability inclusive. National data on HIV need to include disability indicators that can be disaggregated [97].
5. Amplify and include the voices of people living with HIV experiencing disability in decision making, policies and programmes. This includes employing people with disability within HIV programmes and services [97,100].
6. Integration of rehabilitation into HIV care plus delivery of differentiated services that address the unique needs of people living and ageing with HIV experiencing disability. This requires the strengthening and extension of HIV rehabilitation, through advocacy, data collection, commissioning of services and research [97].
7. Advocate for disability inclusion. Disability is a cross-cutting issue, and everybody holds responsibilities and opportunities to enhance the participation and representation of people with disabilities in all spheres of life, including programmatic areas relating to HIV, access to health, education and social protection [98]. Our combined efforts can enhance participation of people with disability in key priority areas, including the obligatory inclusion of disability in funding allocations [99].

to identify the nature and extent of disability among people living with HIV. These tools can be implemented into routine HIV care, included within national HIV survey data collection and support specific research evaluating functioning and disability among people living with HIV. Disability inclusion will advance our approaches to delivering person-centred health care and rehabilitation services.

## I. Acknowledgements

### Funding

This article has been supported by an educational grant from the Gilead Sciences. The company has had no editorial input to the article.

### Conflicts of interests

The author declares no conflicts of interests.

## J References

1. UNAIDS. *Global HIV and AIDS statistics — 2019 fact sheet*. UNAIDS, 2019.
2. Trickey A, May MT, Vehreschild J, et al. Survival of HIV-positive patients starting antiretroviral therapy between 1996 and 2013: a collaborative analysis of cohort studies. *Lancet HIV* 2017; 4(8): e349–e356.
3. Thurn M, Gustafson DR. Faces of frailty in aging with HIV infection. *Current HIV/AIDS Reports* 2017; 14(1): 31–37.
4. Nixon SA, Hanass-Hancock J, Whiteside A, Barnett T. The increasing chronicity of HIV in sub-Saharan Africa: Re-thinking' HIV as a long-wave event' in the era of widespread access to ART. *Global Health* 2011; 7: 41.
5. Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. *Lancet* 2013; 382: 1525–1533.
6. Shah ASV, Stelzle D, Lee KK, et al. global burden of atherosclerotic cardiovascular disease in people living with the human immunodeficiency virus: a systematic review and meta-analysis. *Circulation* 2018; 138(11): 1100–1112.
7. Duncan AD, Goff LM, Peters BS. Type 2 diabetes prevalence and its risk factors in HIV: A cross-sectional study. *PLoS One* 2018; 13(3): e0194199.
8. Mallon PW. Aging with HIV: osteoporosis and fractures. *Curr Opin HIV AIDS* 2014; 9(4): 428–435.
9. Compston J. HIV infection and bone disease. *J Intern Med* 2016; 280(4): 350–358.
10. Nightingale S, Winston A, Letendre S, et al. Controversies in HIV-associated neurocognitive disorders. *Lancet Neurology* 2014; 13(11): 1139–1151.
11. Saylor D, Dickens AM, Sacktor N, et al. HIV-associated neurocognitive disorder –pathogenesis and prospects for treatment. *Nat Rev Neurol* 2016; 12(4): 234–248.
12. Sabin CA, Harding R, Bagkeris E, et al. Pain in people living with HIV and its association with healthcare resource use, well being and functional status. *AIDS* 2018; 32(18): 2697–2706.
13. Chuah FLH, Haldane VE, Cervero-Liceras F, et al. Interventions and approaches to integrating HIV and mental health services: a systematic review. *Health Policy Plan* 2017; 32(Suppl 4): iv27–iv47.



14. Silverberg MJ, Lau B, Achenbach CJ, et al. Cumulative incidence of cancer among persons with HIV in North America: a cohort study. *Ann Intern Med* 2015; 163(7): 507–518.
15. Bloch M. Frailty in people living with HIV. *AIDS Research Therapy* 2018; 15(1): 19.
16. Shippy RA, Karpiak SE. The aging HIV/AIDS population: fragile social networks. *Aging Mental Health* 2010; 9(3): 246–254.
17. Roger KS, Mignone J, Kirkland S. Social aspects of HIV/AIDS and aging: a thematic review. *Can J Aging* 2013; 32(3): 298–306.
18. Siemon JS, Blenkhorn L, Wilkins S, et al. A grounded theory of social participation among older women living with HIV. *Can J Occup Ther* 2013; 80(4): 241–250.
19. Emler CA. 'You're awfully old to have this disease': Experiences of stigma and ageism in adults 50 years and older living with HIV/AIDS. *Gerontologist* 2006; 46(6): 781–790.
20. O'Brien KK, Bayoumi AM, Strike C, et al. Exploring disability from the perspective of adults living with HIV/AIDS: development of a conceptual framework. *Health Qual Life Outcomes* 2008; 6: 76.
21. Banks LM, Zuurmond M, Ferrand R, Kuper H. Knowledge of HIV-related disabilities and challenges in accessing care: qualitative research from Zimbabwe. *PLoS One* 2017; 12(8): e0181144.
22. Hanass-Hancock J, Nixon SA. The fields of HIV and disability: past, present and future. *J Intl AIDS Soc* 2009; 12: 28.
23. Banks LM, Zuurmond M, Ferrand R, Kuper H. The relationship between HIV and prevalence of disabilities in sub-Saharan Africa: systematic review (FA). *Trop Med Int Health* 2015; 20: 411–429.
24. Mactaggart I, Kuper H, Murthy GVS, et al. Measuring disability in population based surveys: the interrelationship between clinical impairments and reported functional limitations in Cameroon and India. *PLoS One* 2016; 11(10): e0164470.
25. Palmer M, Harley D. Models and measurement in disability: an international review. *Health Policy Plan* 2011; 27(5): 357–364.
26. Goering S. Rethinking disability: the social model of disability and chronic disease. *Curr Rev Musculoskeletal Med* 2015; 8(2): 134–138.
27. Morris J (ed). *Encounters with strangers: feminism and disability*. Women's Press, 1996.
28. Jette AM, Field MJ (eds). *The future of disability in America*. US: National Academies Press, 2007.
29. Beaudry J. Beyond (models of) disability? *J Med Philos* 2016; 41(2): 210–228.
30. Oliver M. *Understanding disability: from theory to practice*. Macmillan International Higher Education, 1996.
31. Pfeiffer D. The conceptualization of disability. In Altman BM, Barnartt SN eds. *Exploring theories and expanding methodologies: where we are and where we need to go*. Bingley: Emerald Group, 2001: 29–52.
32. Shakespeare T, Watson N. The social model of disability: an outdated ideology. *Res Social Science Disability* 2001; 2: 9–28.
33. World Health Organization. *How to use the ICF: a practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. October 2013*. Geneva: WHO, 2013. Available at: [www.who.int/classifications/drafticfpracticalmanual.pdf](http://www.who.int/classifications/drafticfpracticalmanual.pdf) (accessed July 2020).
34. Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health* 2011; 11(Supple 4): S3.
35. O'Brien KK, Davis AM, Strike C, et al. Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *J Int AIDS Soc* 2009; 12: 5.
36. Solomon P, O'Brien K, Wilkins S, Gervais N. Aging with HIV and disability: the role of uncertainty. *AIDS Care* 2014; 26(2): 240–245.
37. O'Brien KK, Ibáñez-Carrasco F, Solomon P, et al. Research priorities for rehabilitation and aging with HIV: a framework from the Canada-International HIV and Rehabilitation Research Collaborative (CIHRRRC). *AIDS Res Ther* 2020; 17(1): 21.
38. Cieza A, Sabariego C, Bickenbach J, Chatterji S. Rethinking disability. *BMC Med* 2018; 16(1): 14.
39. World Health Organization. *Constitution of the World Health Organization*. Available at: [www.who.int/about/who-we-are/constitution](http://www.who.int/about/who-we-are/constitution) (accessed July 2020)
40. WHO Quality of Life Group. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Soc Sci Med* 1995; 41(10): 1403–1409.
41. WHO. *Towards a common language for functioning, disability, and health: ICF*. WHO, 2002.
42. Cieza A. Rehabilitation the health strategy of the 21st century, really? *Arch Phys Med Rehabil* 2019; 100(11): 2212–2214.
43. Krug E, Cieza A. Strengthening health systems to provide rehabilitation services. *Neuropsychol Rehabil* 2019; 29(5): 672–674.
44. WHO. *World report on disability*. WHO; World Bank, 2011.
45. WHO. *Training manual on disability statistics*. WHO; United Nations Economic and Social Commission for Asia and the Pacific, 2008.
46. Stucki G, Bickenbach J. Functioning: the third health indicator in the health system and the key indicator for rehabilitation. *Eur J Phys Rehabil Med* 2017; 53(1): 134–138.
47. Madans JH, Loeb ME, Altman BM. Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. *BMC Public Health* 2011; 11(Supple 4): S4.
48. Government Statistical Service. *Measuring disability for the Equality Act 2010: harmonisation guidance, 2019*. Available at: [gss.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/](http://gss.civilservice.gov.uk/policy-store/measuring-disability-for-the-equality-act-2010/) (accessed July 2020).
49. Üstün TB, Kostanjsek N, Chatterji S, et al. *Measuring health and disability: manual for WHO disability assessment schedule WHODAS 2.0*. WHO, 2010.
50. O'Brien KK, Bayoumi AM, King K, et al. Community engagement in health status instrument development: experience with the HIV disability questionnaire. *Prog Community Health Partnersh* 2014; 8(4): 549–559.
51. Altman BM. *International measurement of disability: purpose, method and application*. Springer, 2016.
52. Mont D. Washington Group questions and the Sustainable Development Goals. Washington Group on Disability Statistics, 2017.
53. UK Government. *Definition of disability under the Equality Act 2010*. Available at: [www.gov.uk/definition-of-disability-under-equality-act-2010](http://www.gov.uk/definition-of-disability-under-equality-act-2010) (accessed July 2020).
54. Department for Work and Pensions. *Family Resources Survey 2017/18*. 2019.
55. Brown D, Sedgwick P, O'Brien K, et al. Disability prevalence, domains and associations with age, among people living with HIV accessing routine outpatient HIV care in London, UK: a cross-sectional self-report study. *25th Annual Conference of the British HIV Association (BHIVA)*. Bournemouth, UK. 2–5 April, 2019. Abstract P114.



56. Office for National Statistics. *Measuring disability: comparing approaches. Comparison of the Equality Act measure of disability used in Great Britain to the United Nations recommended measures of disability, based on the Opinions and Lifestyle Survey in January 2019*. ONS, 2019.
57. Kietrys D, Myezwa H, Galantino ML, et al. Functional limitations and disability in persons living with HIV in South Africa and United States: similarities and differences. *J Int Assoc of Provid AIDS Care* 2019; 18: 2325958219850558.
58. Rusch M, Nixon S, Schilder A, et al. Impairments, activity limitations and participation restrictions: prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health Qual Life Outcomes* 2004; 2: 46.
59. O'Brien KK, Solomon P, Bergin C, et al. Reliability and validity of a new HIV-specific questionnaire with adults living with HIV in Canada and Ireland: the HIV Disability Questionnaire (HDQ). *Health Qual Life Outcomes* 2015; 13: 124.
60. Cobbing S, Hanass-Hancock J, Myezwa H. A home-based rehabilitation intervention for adults living with HIV: a randomized controlled trial. *J Assoc Nurses AIDS Care* 2017; 28(1): 105–117.
61. Hanass-Hancock J, Myezwa H, Carpenter B. Disability and living with HIV: baseline from a cohort of people on long term ART in South Africa. *PLoS One* 2015; 10: e0143936.
62. Hanass-Hancock J, Misselhorn A, Carpenter B, et al. Determinants of livelihood in the era of widespread access to ART. *AIDS Care* 2017; 29: 32–39.
63. Myezwa H, Hanass-Hancock J, Ajidahun AT, et al. Disability and health outcomes—from a cohort of people on long-term antiretroviral therapy. *SAHARA J* 2018; 15(1): 50–59.
64. WHO. *Model disability survey: survey manual*. 2017
65. Engler K, Lessard D, Lebouché B. A review of HIV-specific patient-reported outcome measures. *Patient* 2017; 10(2): 187–202.
66. O'Brien KK, Bayoumi AM, Bereket T, et al. Sensibility assessment of the HIV Disability Questionnaire. *Disabil Rehabil* 2013; 35(7): 566–577.
67. O'Brien KK, Solomon P, Bayoumi AM. Measuring disability experienced by adults living with HIV: assessing construct validity of the HIV Disability Questionnaire using confirmatory factor analysis. *BMJ Open* 2014; 4(8): e005456.
68. O'Brien KK, Kietrys D, Galantino ML, et al. Reliability and validity of the HIV disability questionnaire (HDQ) with adults living with HIV in the United States. *J Int Assoc of Provid AIDS Care* 2019; 18: 2325958219888461.
69. Brown DA, Simmons B, Boffito M, et al. Evaluation of the psychometric properties of the HIV Disability Questionnaire among adults living with HIV in the United Kingdom: A cross-sectional self-report measurement study. *PLoS One* 2019; 14(7): e0213222.
70. WHO. *Rehabilitation in health systems: guide for action*. 2019.
71. Heinemann AW, Feuerstein M, Frontera WR, et al. rehabilitation is a global health priority. *Arch Phys Med Rehabil* 2020; 101(4): 271–272.
72. WHO. *Rehabilitation in health systems*. 2017.
73. Stucki G, Bickenbach J, Gutenbrunner C, et al. Rehabilitation: the health strategy of the 21st century. *J Rehabil Med* 2018; 50(4): 309–316.
74. WHO. *The need to scale up rehabilitation*. 2017.
75. Worthington C, Myers T, O'Brien K, et al. Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. *AIDS Patient Care STDs* 2005; 19(4): 258–271.
76. O'Brien KK, Solomon P, Trentham B, et al. Evidence-informed recommendations for rehabilitation with older adults living with HIV: a knowledge synthesis. *BMJ Open* 2014; 4(5): e004692.
77. Lazarus JV, Safreed-Harmon K, Barton SE, et al. Beyond viral suppression of HIV—the new quality of life frontier. *BMC Medicine* 2016; 14(1): 94.
78. Webster P. UNAIDS survey aligns with so-called fourth 90 for HIV/AIDS. *Lancet* 2019; 393(10187): 2188.
79. The Lancet HIV. Living well with HIV. *Lancet HIV* 2019; 6(12): e807.
80. McPherson K. Rehabilitation nursing – a final frontier? *Int J Nurs Stud* 2006; 43(7): 787–789.
81. Spasser MA, Weismantel A. Mapping the literature of rehabilitation nursing. *J Med Libr Assoc* 2006; 94: E137–E142.
82. Watson S. HIV complex care and care coordination: the nurse's role. *HIV Nursing* 2018; 18(2): 38–46.
83. O'Brien KK, Brown DA, Corbett C, et al. AIDS Impact special issue—broadening the lens: recommendations from rehabilitation in chronic disease to advance healthy ageing with HIV. *AIDS Care* 2020; 32(Suppl 2): 65–73.
84. National HIV Nurses Association. *Annual health review for people living with HIV: a good practice guide*. NHIVNA, 2017.
85. Kall M, Kelly C, Auzenberg M, Delpech V. *Positive Voices: The National Survey of People Living with HIV - findings from the 2017 survey*. London: Public Health England, 2020.
86. O'Brien KK, Tynan A, Nixon SA, et al. Effectiveness of aerobic exercise for adults living with HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. *BMC infect Dis* 2016; 16: 182.
87. O'Brien KK, Tynan A, Nixon SA, et al. Effectiveness of progressive resistive exercise (PRE) in the context of HIV: systematic review and meta-analysis using the Cochrane Collaboration protocol. *BMC infect Dis* 2017; 17(1): 268.
88. Webel A, Swanson B. Let's get physical. *J Assoc Nurses AIDS Care* 2020; 31(3): 266–267
89. Montoya JL, Jankowski CM, O'Brien KK, et al. Evidence-informed practical recommendations for increasing physical activity among persons living with HIV. *AIDS* 2019; 33(6): 931–939.
90. de Boer H, Andrews M, Cudd S, et al. Where and how does physical therapy fit? Integrating physical therapy into interprofessional HIV care. *Disabil Rehabil* 2018; 41(15): 1768–1777.
91. Petroczi A, Hawkins K, Jones G, Naughton D. HIV patient characteristics that affect adherence to exercise programmes: an observational study. *Open AIDS J* 2010; 4: 148–155.
92. Brown D, Claffey A, Harding R. Evaluation of a physiotherapy-led group rehabilitation intervention for adults living with HIV: referrals, adherence and outcomes. *AIDS Care* 2016; 28(12): 1495–1505.
93. Worthington C, Myers T, O'Brien K, et al. Rehabilitation professionals and human immunodeficiency virus care: results of a national Canadian survey. *Arch Phys Med Rehabil* 2008; 89(1): 105–113.
94. World Health Organization. *WHO global disability action plan 2014–2021: better health for all people with disability*. WHO, 2015.
95. United Nations. *Transforming our world: The 2030 agenda for sustainable development*. UN, 2016.
96. United Nations. *Convention on the Rights of Persons with Disabilities*. New York: UN, 2008.
97. Joint United Nations Programme on HIV/AIDS (UNAIDS). *Disability and HIV*. Geneva: UNAIDS, 2017.
98. UN General Assembly. *Political declaration on HIV and AIDS: on the fast-track to accelerate the fight against HIV and to end the AIDS epidemic by 2030*. New York: UN, 2016.

99. Hanass-Hancock J, Chappell P, Myezwa H, et al. Committing to disability inclusion to end AIDS by 2030. *Lancet HIV* 2016; 3(12): e556–e557.
100. Mission CB. Inclusion made easy: A quick program guide to disability in development. Melbourne: CBM Australia, 2012.
101. Bettger JP, Thoumi A, Marquevich V, et al. COVID-19: maintaining essential rehabilitation services across the care continuum. *BMJ Global Health* 2020; 5(5): e002670.
102. Hargreaves J, Davey C, Group for lessons from pandemic HIV prevention for the COVID-19 response. Three lessons for the COVID-19 response from pandemic HIV. *Lancet HIV* 2020; 7(5): e309–e311.
103. Hanass-Hancock J, Alli F. Closing the gap: training for healthcare workers and people with disabilities on the

interrelationship of HIV and disability, *Disabil Rehabil* 2015; 37(21): 2012–2021.

104. Howarth A, Burns F, Chadwick D et al. *British HIV Association standards of care for people living with HIV*. BHIVA, 2018.

105. Wesson P, Handcock MS, McFarland W, et al. If you are not counted, you don't count: estimating the number of African-American men who have sex with men in San Francisco using a novel Bayesian approach. *J Urban Health* 2015; 92(6): 1052–1064.

---

Correspondence: Darren Brown  
Email: darren.brown@chelwest.nhs.uk  
Twitter: @darrenabrown