



Lessons learned

Including disability in HIV policy and programming: Good practices drawn from country-based evidence

Technical Resources Division
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Lesson learned

Including disability in HIV policy and programming: Good practices drawn from country-based evidence

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of the study. The first author (SMHJ) was involved in the design, data collection, data analysis and writing of the manuscript. The other authors were involved in the design, data collection and writing of the manuscript.

CONCLUSIONS

The present study shows that the use of a 2000 kcal diet can be used as a safe and effective weight reduction strategy in obese patients with type 2 diabetes. The weight reduction was achieved without any adverse effects on glycaemic control, blood pressure, lipid profile or quality of life. The weight reduction was maintained for 1 year. The weight reduction was achieved without any adverse effects on glycaemic control, blood pressure, lipid profile or quality of life. The weight reduction was maintained for 1 year.

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DECLARATION OF INTEREST

The authors declare that they have no competing interests. The authors also declare that they have no financial interests.

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Foreword

Since its foundation in 1982 to help Cambodian amputees living in refugee camps along the Thai border, Handicap International has continued working alongside people with disabilities and other vulnerable groups. Our actions and witness-bearing focus on responding to their essential needs, improving their living conditions and promoting respect for their dignity and fundamental rights. We run projects in 59 countries in the fields of Civil Society Support, Rehabilitation, Prevention and Health and Social Inclusion, as well as mine action and emergency response projects.

Handicap International was one of the first disability-focused organisations worldwide to actively respond to the HIV epidemic in Burundi in 1994. It rapidly followed suit in other eastern and southern African countries such as Rwanda, Kenya, Ethiopia, Somalia, and Mozambique, working with vulnerable groups—especially people with disabilities—affected by HIV and AIDS. In West Africa, although the general HIV prevalence among adults appeared to be relatively low in comparison to eastern and southern African countries, observations by people with disabilities and demands from disabled people's organisations on the ground prompted Handicap International to address the vulnerability of women and men with different types of disabilities to the emerging epidemic. In South-East Asia, in light of field observations of sexual violence and gross human rights violations preventing women and girls with disabilities from accessing basic sexual and reproductive health services, Handicap International launched action to ensure HIV prevention and services for people with disabilities.

Hence, over time, Handicap International has gained significant experience and developed good practices with regard to including disability in HIV policy and programming. Indeed, the organisation has learned important lessons about programmatic and political processes and dynamics, before the international community had even recognised disability as an issue to be addressed.

This paper is the result of more than a decade of field experience in HIV and disability. It is intended for organisations, agencies, programme managers and individuals dedicated to achieving universal access and the inclusion of the most vulnerable and most discriminated against populations.

Ludovic Bourbé

Director of Technical Resources Division

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Preface

HIV and AIDS remains one of the most widespread disabling epidemics worldwide. The disease leads to impairments, activity limitations and reduced social participation. According to the World Health Organization and World Bank, more than a billion people in the world today experience disability. A significant number of disabled people live in Sub-Saharan Africa where they are considered to be at risk or at higher risk of HIV infection than non-disabled people—especially women with disabilities. In its recent “Gap report”, UNAIDS highlighted a lack of awareness by society, violence and sexual abuse, discrimination in health-care settings and low HIV awareness and risk perception among people with disabilities as key factors in their heightened risk and vulnerability to infection.

Over the years there has been a growing body of research as well as an increasing number of field projects focusing on the intersection of HIV and disability, in particular in southern and eastern Africa. However quantitative evidence related to the vulnerability of people with disabilities to HIV remains scarce and so far there has been limited documentation of the country-based evidence underpinning good practices. In order to redress this situation and communicate on what actually works when it comes to mainstreaming disability into the HIV and AIDS response, Handicap International has decided—on the basis of more than 10 years of experience in both fields—to capitalise on the lessons learned from good practices on a range of projects implemented in Sub-Saharan Africa and South East Asia.

This paper is primarily intended for AIDS organisations, the disability community and development partners. The good practices presented here are also intended to inspire and motivate other organisations and agencies to fully embrace the principle of universal access for all, as stipulated in the UN Convention on the Rights of Persons with Disabilities.

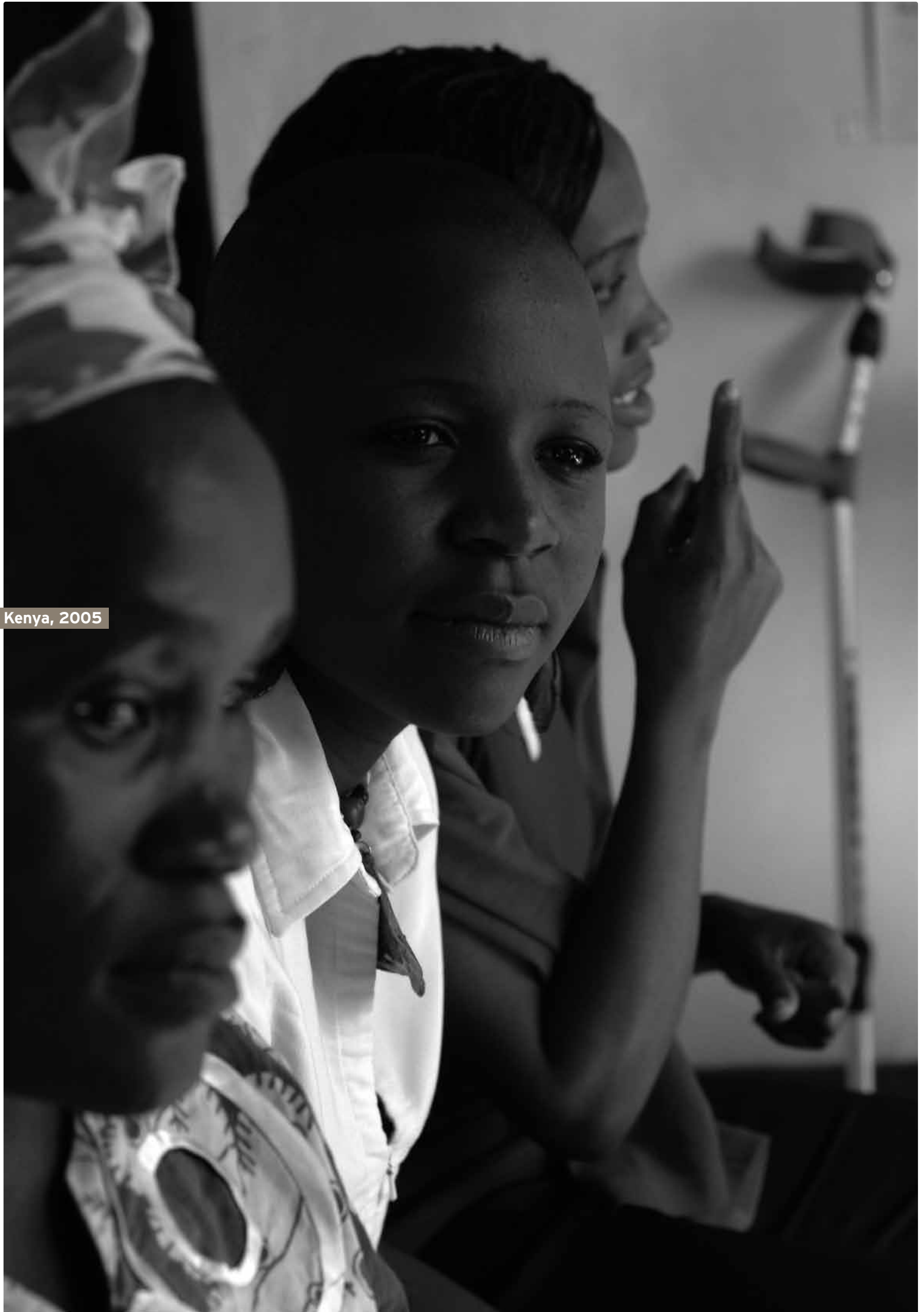
I would like to thank all the respondents, project beneficiaries and actors for providing us with their invaluable testimony and views which have served to enrich this document. I am also grateful to both internal and external contributors for their input and feedback: Dr Aïda Zerbo and her team (Handicap International, Senegal); Mahlet Tigneh, Esknder Dessalegne and their team (Handicap International, Ethiopia); Elie Mugabowishema (Handicap International, Rwanda); Caroline Bii and her colleagues (Handicap International, Kenya); Dr Jill Hanass-Hancock (HEARD, South Africa); Dr Paul Chappell (University of Johannesburg, South Africa); and Phillimon Simwaba (DHAT, Zimbabwe).

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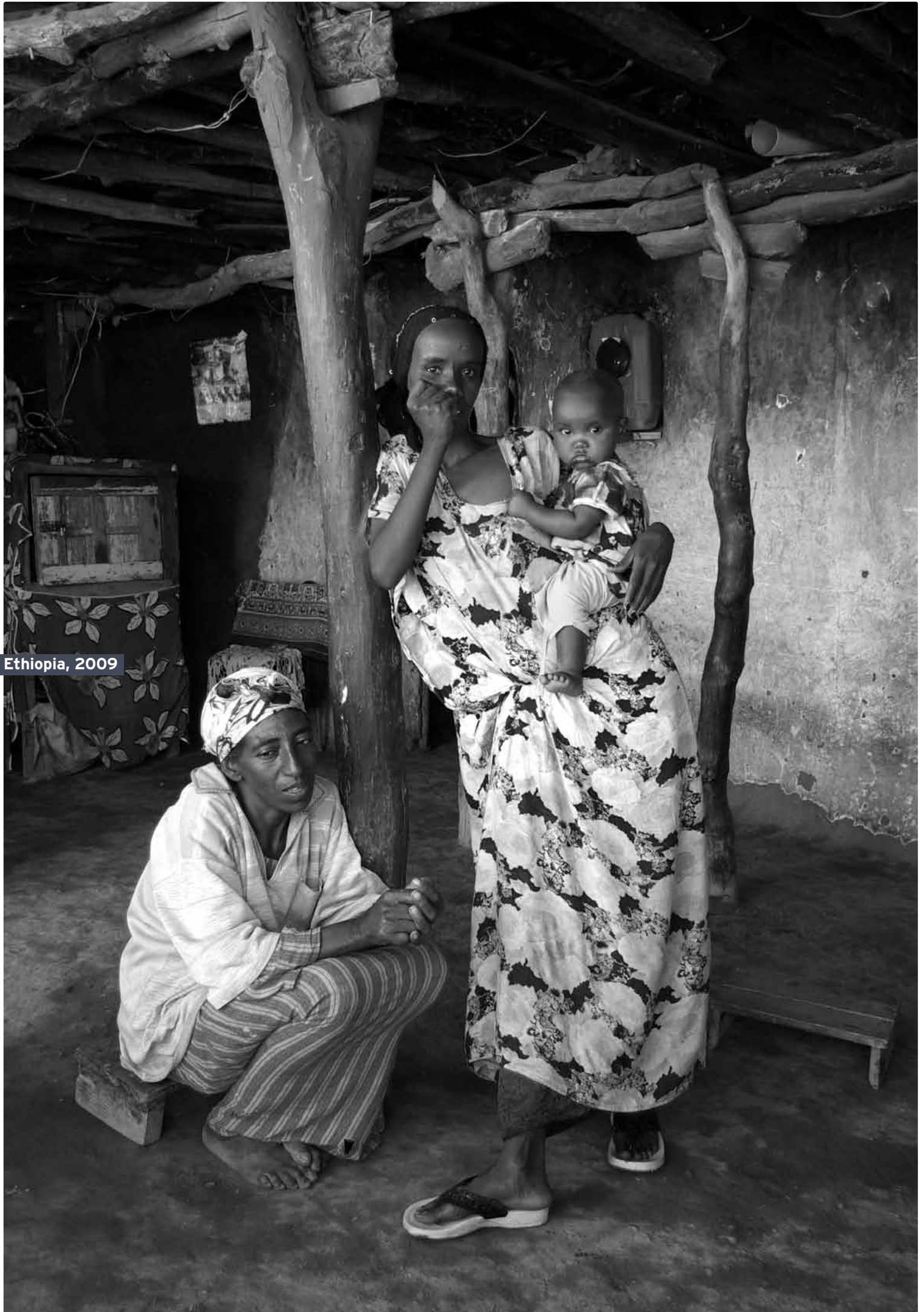


Kenya, 2005

The purpose of this document is to share good practices and processes concerning the inclusion of disability issues in HIV policy and programming, drawing on specific experiences in Senegal, Ethiopia, Kenya, Rwanda and Cambodia and on lessons learned at international AIDS conferences.

More specifically, it is intended to **1)** provide a clear indication to HIV and AIDS practitioners that disability mainstreaming in HIV and AIDS is indeed possible and workable in various contexts and by implementing specific steps/initiatives; **2)** transfer concrete knowledge and practices to disability stakeholders, including disabled people's organisations, on how to work in HIV and AIDS; and **3)** persuade HIV-related development partners that more investment is needed to develop this knowledge base in order to bring about practical changes at micro, meso and macro levels, as well as among the population. Furthermore, the good practices shared here can be used and replicated in other contexts and countries if/when they are adapted to other situations and based on the needs of people with disabilities and communities.

This paper follows on from Handicap International's policy paper¹ on "Inclusive and Integrated HIV and AIDS Programming" (to sexual and reproductive health and gender-based violence) and the projects summary document "From Africa to South East Asia: Handicap International's work on HIV and AIDS"² and builds on the principles outlined in the practical guide on "Access to Services for Persons with Disabilities"³. On the basis of the good practices highlighted here, Handicap International intends to replicate and scale-up the lessons learned in its future disability-inclusive HIV programming and policy planning and implementation.



Ethiopia, 2009

Principles and benchmarks

Handicap International has been involved in the global HIV response since 1994 when it implemented its first field interventions in Burundi. Handicap International was one of the first organisations to highlight the interrelation between HIV and disability in developing countries, spearheading the Africa Campaign on Disability and HIV and AIDS⁴. This campaign's major achievement was the Kampala Declaration⁵ which alerted NGOs, disabled people's organisations (DPOs), mainstream AIDS organisations, research and academic institutes, UN bodies and donor agencies to the strategic importance of including disability in HIV and AIDS policies and programming. Handicap International has field experience of implementing HIV and AIDS programming in Ethiopia, Somaliland/Puntland, Kenya, Rwanda, Burundi, Mozambique, Mali, Senegal, Cambodia, Laos and Vietnam.

HIV and AIDS remains one of the most widespread disabling epidemics worldwide. The disease leads to impairments, activity limitations and reduced social participation. This has a severe impact on the quality of life, both for people infected with HIV and AIDS and their families and communities⁶. It is now considered a chronic and cyclical disease, with periods of wellness and illness.

The main reason for Handicap International's operational focus on HIV and AIDS is the high vulnerability to HIV of people with disabilities who constitute approximately 15.6% (11.8–18.0%) of the world's population⁷. Based on a recent meta-analysis of HIV prevalence among adults with disabilities in Sub-Saharan Africa⁸, data show there is a gradient in the risk of HIV infection according to gender and disability status, with risk increasing from 1.48 in men with disabilities to 2.21 in women with disabilities when compared to non-disabled men. Moreover, based on studies published in the *Lancet*, the prevalence of violence against people with disabilities—irrespective of the type of disability—is 1.3 times higher than in the general population, 1.39 times higher among women with disabilities and 3.86 times

higher among people with mental health conditions⁹. Children with disabilities are 3.7 times more likely than their non-disabled peers to be the victims of violence¹⁰. These findings confirming that people with disabilities are highly vulnerable to HIV and AIDS are congruent with the general recognition that marginalised, stigmatised communities with limited access to basic human rights are frequently at higher risk of HIV infection and feel the impact of HIV and AIDS more significantly¹¹.

This view challenges the common misconception that people with disabilities are sexually inactive and do not require HIV or sexual reproductive health services. Indeed there is a broad range of discriminatory practices and social stigma contributing to the vulnerability and social exclusion of people with disabilities. Launched at the International AIDS Conference in Melbourne in July 2014, the UNAIDS Gap Report explicitly indicated that the key factors contributing to the vulnerability of people with disabilities are their own low HIV awareness and risk perception, discrimination in health-care settings, violence and sexual abuse and lack of awareness by the society¹².

This international acknowledgement is crucial if donors are to fully support civil society organisations promoting accessibility and universal access to HIV information, prevention, treatment, care and support services **for all**; strategically invest in one of the world's biggest minorities (15% of the world's population) so that they do not constitute the next hidden generation of HIV propagation; and contribute to inclusive post-2015 development processes to durably reverse the AIDS epidemic.

The lesson-learning methodology used by Handicap International to capture good practices from various countries was based on a series of activities undertaken over time (see Figure 1). Specific care was taken at the start of the process to select good practices among all the different countries

Rapid review of literature on HIV and disability

Review of all HIV and disability projects at Handicap International

Based on criteria, **selection** of initiatives focused exclusively on disability mainstreaming

Write-up of each selected good practice explaining processes and why

Validation of good practice by field teams

Corroboration and feedback from communities and stakeholders

Editing, translation, design, printing and dissemination

where Handicap International had been implementing disability inclusion in HIV and AIDS initiatives.

Given the purpose of good practices and their potential replication and scaling-up, it was important to use criteria enabling a thorough analysis and reflection on what works in various contexts with regard to disability inclusion at various levels of HIV-related services and policy-making. The good practice criteria were as follows:

- **Initiatives showing demonstrable impact:** clearly achieving expected results and recording positive impact among project stakeholders and partners, corroborated by feedback describing positive changes.
- **Nature of replicability:** a specific action, approach or technique which Handicap International and others could feasibly replicate, adapt or scale up in other contexts and programmes.
- **Efficiency:** a practice which is efficient in terms of time, finances and human resources.
- **Sustainability:** potential for local actors to be able to develop or sustain an action, approach or technique in the future.
- **People-centred:** practices related to service provision which respect the concept of individual users being actively involved in any decisions which concern them.
- **Initiatives that conform to a broader set of guiding principles and shared values** such as non-discrimination, full and effective participation in society, equality of opportunity and accessibility.

Based on the above criteria, six initiatives were selected: **1)** Disability inclusion in the national AIDS strategic plan in Senegal; **2)** Inclusion of disability by mainstream AIDS organisations and implementing partners in Ethiopia; **3)** Capacity-building of DPOs for increased organisational development in Rwanda; **4)** Disability inclusion at HIV services level in Kenya; **5)** A specific initiative for deaf women and the integration of sexual violence protection in Cambodia; and **6)** Inclusive international AIDS conferences.

Figure 1—Lesson learning process for capturing good practices

...sation et la
discrimination des
femmes vulnérables



Senegal, 2008

...LIGE
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...CRIMINA

...P FORMEDUC
...C P H.

HANDICAP INTERNATIONAL
Vivre debout

The Secretariat of the
African Decade
of Persons with Disabilities

HANDICAP

Initiative 1

Inclusion of disability in the National AIDS Strategic Plan in Senegal

This example of good practice concerns a project implemented in Senegal and focused on strengthening the local HIV and AIDS response for people with disabilities. The project, which started in March 2008 and ended in June 2011, was part of a regional initiative that also involved Mali and Burundi and was co-funded by the *Agence Française de Développement* (international development agency of France), World Learning/USAID and Handicap International. Its main objectives were to promote access to HIV prevention, treatment, care and support services for people with disabilities and to encourage their participation in HIV and AIDS programming.

As a result of this project, more than a thousand people, including people with disabilities, were counselled and tested for HIV in Senegal; 100 local initiatives on accessibility and social participation were put in place to improve access to HIV prevention and care services for people with disabilities; health/HIV-related personnel were trained on disability inclusion and basic sign language; and a Platform on Disability and HIV was set up to advocate for the mainstreaming of disability issues in national HIV and AIDS policy and programming.

One of the key successes of the project was the inclusion of disability in Senegal's 2011–2015 National AIDS Strategic Plan (NSP)¹³. This Plan foresees specific HIV prevention services and allocates resources for women and men with disabilities. The government of Senegal has thus added people with disabilities to its official list of populations vulnerable to HIV infection. This represents a major breakthrough and has sent a strong message to international donors and the mainstream development

organisations engaged in counteracting the HIV epidemic in Senegal, affirming that failure to address the vulnerability to HIV and AIDS of people with disabilities is no longer acceptable.

A

Description of the context before the practice

Prior to Handicap International's regional HIV and disability project, mainstream HIV and AIDS programming and activities in Senegal did not target groups of people with disabilities. The common perception was that people with disabilities were sexually inactive and so not at risk of HIV infection and not in need of HIV-related information, prevention and services. Furthermore, health care services were not catering to people with disabilities and the health care approach was not adapted to the specific needs of women and men with different disabilities. Similarly the 2007–2011 NSP (guidelines for HIV programming in the country) did not include people with disabilities in its key list of vulnerable populations deserving priority attention in the national HIV response, a list that otherwise included sex workers, men having sex with men, women, orphans and vulnerable children. Over the years, this exclusion had major consequences with regard to access, prioritising, resource allocation and donor investment in a country still highly dependent on foreign assistance for its internal development.

In order to redress this situation, Handicap International, alongside local partner organisations including the Society for Women and AIDS in Africa (SWAA)–Senegal, the Federation of Persons with Disabilities of Senegal (FSAPH), the Outpatient Treatment Centre of Fann (CTA) and the National AIDS Council (NAC), set up a project to facilitate access by people with disabilities to HIV

Initiative 1

prevention information and services, both in the region of the capital, Dakar, and in Casamance, a southern province flanked by Gambia and Guinea Bissau.

B

Description of the good practice

The good practice that led to disability being included in the last Senegalese NSP is the result of a combination of key programmatic and advocacy activities and epidemiological evidence confirming that people with disabilities in the region of Dakar were indeed at higher risk of HIV than the general non-disabled population in the same region.

Below is a list of some of the strategies used in achieving the inclusion of people with disabilities in the last NSP:

- Advocacy initiatives among the National AIDS Council's (NAC) decision-makers, especially at strategic meetings and during the drafting of the last NSP in 2011.
- Regular feedback to the multi-stakeholder¹⁴ National Platform on Disability and HIV on the project's programmatic progress and successes in terms of accessibility.
- Implementation of a seroprevalence and Knowledge, Attitudes and Practices (KAP) survey among people with disabilities in the region of Dakar from February to March 2011 prior to the decision on who to include in the NSP's final list of Vulnerable Populations.
- Dissemination of the study's results to the NAC director and directors of other departments, such as the Monitoring, Evaluation and Research Department, showing that HIV prevalence among people with disabilities in the region of Dakar was almost twice that of non-disabled people (1.18%, CI95% (0.37–2.0) versus 0.7% among the general non-disabled population). The feminisation of HIV also appeared to be corroborated

by the results of this study, with a higher HIV prevalence rate among women with disabilities (1.35%, CI95% (0.03–2.67)¹⁵.

- Strategic information on the project's results was shared with the NAC on a regular basis with a view to ensuring the integration of a paragraph on disability in the HIV prevention section of the NSP, as well as the specific inclusion of people with disabilities in HIV prevention activities and in the resource allocation section.
- Several follow-up meetings were necessary to ensure that the needs of people with disabilities were taken into account from the initial draft version of the new NSP right through to the final version. This was particularly important as experience in other countries (such as in Zimbabwe) has taught us that nothing can be taken for granted and that constant follow-up is essential to make sure that disability issues do not fall by the wayside and are still there in the final official version of the NSP. Thanks to extreme vigilance and constant follow-up on the part of the project's management, this was not the case in Senegal.

C

Most significant changes

Of all the changes related to disability inclusion in Senegal, the most significant was the decision by the NAC in 2011 not only to include people with disabilities in the human rights section of the NSP, but also to target them for HIV prevention services and allocate specific financial resources for addressing their HIV-related needs. People with disabilities were clearly identified as a priority target group and their vulnerabilities highlighted.

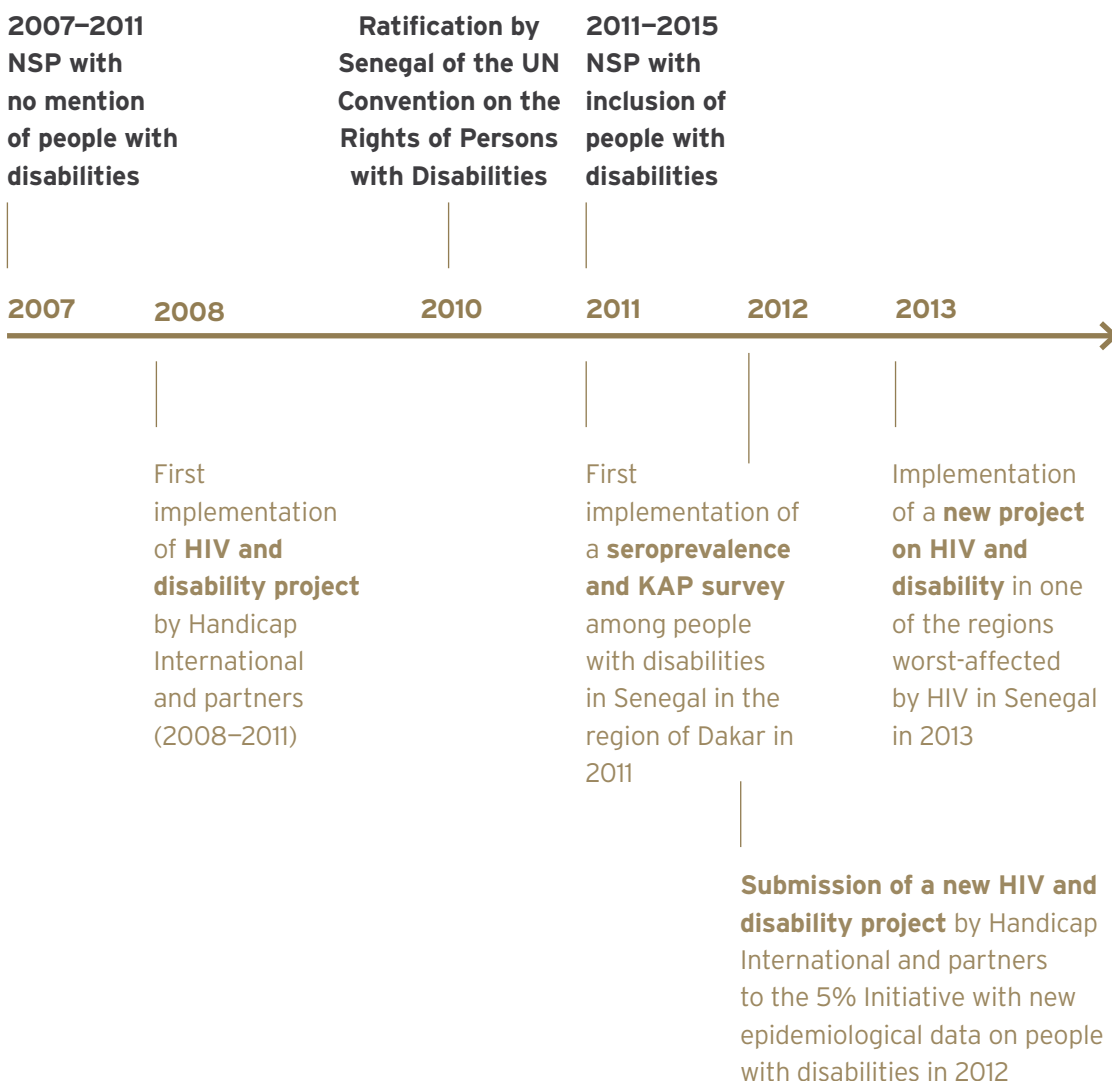
People with disabilities have also been targeted in the national HIV-related results framework with regard to the prevention of new HIV infection through greater

promotion of condom use. A budget plan has been drawn up to address HIV prevention issues among people with disabilities, and they are also to be included in nationwide epidemiological and behavioural surveys.

Given the competition for limited resources and the need for epidemiological evidence in a medicalised sector such as HIV /AIDS, the timely implementation by Handicap International of a seroprevalence and KAP survey among people with disabilities provided quantitative arguments for targeting one of the most invisible groups at risk of HIV, a group not yet on the radar of national policy-makers or public service providers.

Another significant change resulting from the inclusion of people with disabilities in the HIV response has been the approval of a new project on HIV and disability submitted for funding in 2012. The belief is that this new epidemiological data on the level of disabled people’s vulnerability to HIV, along with other convincing quality project components, helped convince the French Government’s 5% Initiative to take the bold decision to invest in the project. This decision thus appears to have been based on project-specific documentation demonstrating the needs and gaps that people with disabilities still face when trying to access HIV and AIDS information and services in various parts of the country.

Figure 2—Illustration of the sequence of events that contributed to improving access by people with disabilities to HIV prevention and response activities in Senegal



Initiative 1

Although the new project is still in the early stages of implementation, it aims to reach around 11,000 people with disabilities within three years in the region of Ziguinchor in the south of Senegal where HIV prevalence is estimated to be among the highest. It is also expected that the project will enable hundreds of people with disabilities, including disabled pregnant women, to receive counselling and testing for HIV. As such, it will help achieve the national objective of ensuring as many people as possible benefit from HIV prevention and enrolling people living with HIV as early as possible in national antiretroviral programmes in order to help reverse the HIV trend both at national and regional levels.

D

Impact statements

- **From Dr Simon Hambarukize, technical manager for SWAA Senegal:** "... Before Handicap International's project, there was no mention of disability in the NSP. As an actor involved in drafting the NSP, we advocated for disability to be part of it. We were sensitised by Handicap International's regional project which showed the intersection of HIV and disability. This project has shown the way, enabled us to take action and raise the interest of the whole country on disability via information, education and communication at national level."
- **From Prof Doudou Ba, President of the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria in Senegal:** "Including people with disabilities in the Country Coordinating Mechanism (of the Global Fund to Fight AIDS, Tuberculosis and Malaria) is important to help shape the content of future NSPs, especially when this is undertaken by disability-focused organisations such as Handicap International."

- **From Mrs. Kankou Coulibaly, Public Sector Manager, National AIDS Council of Senegal:** "The perseverance and commitment shown by the team from Handicap International convinced us to take action to include disability in the NSP... Gathering evidence of the need to include people with disabilities was facilitated by Handicap International. However this has not yet enabled us to create a specific unit on disability within the National AIDS Council."

E

Facilitating factors that made this practice successful

The success of this practice was not left to chance. The following factors helped achieve inclusion of people with disabilities in the country's response to HIV:

- **Financial resources for conducting a seroprevalence and KAP survey among people with disabilities:** A systematic review of HIV prevalence among adults with disabilities living in Sub-Saharan Africa¹⁶ revealed the paucity of HIV prevalence studies focusing on people with disabilities. There are a number of possible reasons for this: the inclusion of disability in the HIV response and research was not a national priority; research and monitoring & evaluation departments did not understand or recognise the need to collect data on people with disabilities; disabled people's organisations (DPO) were not advocating strongly enough for the rights of people with disabilities; and there was a lack of financial investment in quantitative studies on HIV and disability. Luckily, the initial HIV and disability project implemented by Handicap International and its partners from 2008–2011 planned such a study and was given the green light by its institutional donors. This green light was crucial, as not all donors are willing

to fund projects wanting to conduct this kind of survey. But it was this collection of evidence that swung the case for mainstreaming disability in HIV prevention, treatment, care and support, as only by knowing just how vulnerable disabled people were to HIV could decision-makers take sound and evidenced-based programmatic and policy decisions.

- **Technical resources for conducting such a study:** This study was undertaken by well-reputed national laboratories (*Laboratoire de Bactériologie et Virologie, Agence pour la Promotion des Activités de Populations-Sénégal* and *Réseau Africain de Recherche sur le Sida*) and supervised by the Professor Souleymane Mboup, one of the world's leading scientists who helped discover HIV-2. As a result, the study gained credibility during its dissemination phase among key stakeholders such as the National AIDS Council and members of the Country Coordinating Committees (CCM) of the Global Fund to Fight AIDS, Tuberculosis and Malaria, who carry a lot weight in national HIV-related programmatic decisions.
- **Ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD):** In September 2010, the Government of Senegal ratified the UNCRPD. Ratification of the UNCRPD is binding and requires States to progressively put in place accessible measures for the rights of people with disabilities. Article 25 (on health) and Article 31 (on statistics and data collection) might have played a role in prompting Senegal to meet its obligations towards people with disabilities and include them in health and HIV and AIDS initiatives.
- **Ownership of and buying-in to the project by main project partners:** The fact that project partners, such as the SWAA-Senegal's buy-in and ownership of the project interventions and seroprevalence and KAP survey was decisive in helping to win over NAC and CCM representatives. The study results were conclusive and the main project

partners played a key role in promoting their importance in an attempt to ensure that people with disabilities were not only taken into consideration by organisations such as Handicap International, but more importantly by the State itself as part of a more effective response to the country's HIV epidemic.

- **Participation of disabled people's organisations (DPO) in the mobilisation of disabled survey respondents:** Given the novelty of this survey among people with disabilities in Senegal, it was essential to work collaboratively with members of DPOs to mobilise disabled survey respondents. The participation of DPOs was instrumental in helping survey enumerators to find households with disabled family members in the Dakar region. People with disabilities are often hard to reach, so the DPOs' contribution helped gain people's trust, making it easier to conduct the survey.
- **Extreme dynamism and commitment on the part of the programme director and project manager:** All of the above facilitating factors were important to ensuring the inclusion of disability in the most recent NSP in Senegal. However, this could not have been achieved without the constant and considerable efforts furnished by the project management team. Marathon meetings with and visits to the NAC were undertaken up until a few days before the NSP went to the printers. This is another illustration of how maintaining open working relationships in development can lead to significant changes.

F

Barriers or challenges

- **Lack of reliable national data on disability:** Senegal is no different from many other countries when it comes to the availability of reliable national statistics on disability. One of the main reasons for this lack of data is the use of a disability classification that may be too restrictive and/or medical in its definitions. As a result, some people with disabilities may have been overlooked in census and survey processes. These factors influenced the choice of the sampling methodology and frame used in the seroprevalence and KAP survey undertaken in 2011. For example, if the Washington Group¹⁷ questions on disability had been used in this project, there would probably have been more people with a broader range of disabilities captured in the survey sample.
- **Budget not quite sufficient:** Although the project had budgeted for the survey, this budget was not sufficient. With a bigger budget, the survey managers could have used the Washington Group questions on disability and another sampling frame which would have involved a larger number of households in the first stage of sampling and provided with a more representative and inclusive sampling i.e. with more people with different types of disabilities.
- **Lack of time to sample and work with people with disabilities:** One month was allocated for data collection. In hindsight, it would have been better to have more than a month for data collection among people with disabilities. Furthermore, some respondents in the randomly selected households had moved, so further sampling was needed to obtain the required sample size.

- **Obtaining approval for the survey:** Given the quantitative and qualitative nature of a survey involving HIV testing among people with disabilities and the fact that this survey contained sensitive questions, approval was needed from both the project scientific and national ethical committees. Obtaining this approval took time and meant the survey could not be conducted until the project's final year.

Future projects should consider all these challenges when planning a seroprevalence and KAP survey among people with disabilities, especially if this is a first-time intervention in the country concerned.

G

Analysis

This inclusion of and sensitivity towards disability issues in a West African country's NSP is a significant breakthrough. The case study has shown that implementing a seroprevalence and KAP survey among people with disabilities can be a powerful means of influencing policy and decision makers at both National AIDS Council level and among institutional donors. This type of intervention can be easily replicated provided that appropriate technical resources and enough finance and time are available. If these essential factors are overlooked or underestimated, it would be detrimental to its efficiency in the long run. Furthermore, undertaking a quantitative and qualitative survey among people with disabilities has been seen here to yield important results and provide the evidence needed to accelerate the expansion of HIV prevention and services to all populations at risk of HIV, including people with disabilities. It can therefore save time and avoid the implementation of many smaller-scale pilot projects that could ultimately have limited impact on the access of people with disabilities to HIV

prevention, treatment, care and support services. More importantly, this initiative shows that disability can be an integral part of all sections of an NSP and result in the mainstreaming of disability in HIV services, HIV-related indicators, budget allocation, and national-based research and monitoring and evaluation mechanisms. This would not only show a government's commitment to reaching "zero infection, zero AIDS-related deaths and zero discrimination"¹⁸ by targeting everyone at risk, but would also help tackle the HIV epidemic by leaving no one behind.

H

Recommendations for HIV and AIDS practitioners

The key recommendations related to this good practice are as follows:

- For every HIV and disability project, always allow for appropriate technical and sufficient financial resources to conduct a survey on seroprevalence and KAP among people with disabilities, using a reliable sampling methodology and disability statistics based on the Washington group disability-related questions. This adds weight when it comes to evidence-based advocacy.
- Allow enough time to work with people with different disabilities who are often hard to reach. Doing business as usual is no longer possible as methodologies need to be adapted to the different needs of people with different types of impairments. Therefore, allowing time to be flexible is important if a primary project objective is for quality results to achieve inclusion.
- Exploit and use all available international and regional tools/policies/conventions that governments have signed and/or ratified in order to hold them to their commitments. Knowing where the disability-related gaps exist at policy level helps in devising a more solid advocacy plan for use with the National AIDS Council and other relevant governmental bodies.
- Be part of all national strategic meetings on statistics collection at the NAC level or insist on being invited. Only those who have a voice at the decision-makers' table will be in a position to promote and represent the rights of people with disabilities in the HIV response.
- Involve DPOs and their constituencies. They know what facilitating factors and barriers are encountered by people with disabilities with regard to HIV and AIDS.
- Do not underestimate the power of person-centred working relations at the human being level, ensuring timely follow-up with busy national stakeholders.
- From the very start of the project, ensure the buy-in and full ownership of its various components by the main project partners. This will be more effective and efficient in the long run, and will yield more durable results than if the project is implemented without real participation by all.

Initiative 2

Inclusion of disability by mainstream US-funded AIDS organisations and implementing partners in Ethiopia

This good practice concerns a pilot project implemented from 2010 to 2013 and funded by World Learning/USAID, with the support of the PEPFAR Coordination Office of Ethiopia. The project focused on improving access to HIV prevention and services for people with disabilities via selected USAID- and PEPFAR-funded key AIDS organisations and their implementing partners in Addis Ababa, Ethiopia. The main partners were: Population Council (PC), Population Service International (PSI), John Hopkins University (JHU) *Tsehai Project*, IntraHealth, National AIDS Resource Centre (NARC) and Addis Ababa University (AAU) March Project; their implementing partners were: *Biruh Tesfa Project*, Mekdim National Association, Saris Health Centre, Minelik Referral Hospital, Brothers of Good Work and Addis Ababa University Students' Disability Centre.

When this innovative project aimed at increasing the understanding and inclusiveness of disability issues by mainstream AIDS organisations was launched in 2010, disability was not yet included in the 2004–2008 National AIDS Strategic Plan (NSP), still in use at that time. Working directly with mainstream US-funded AIDS organisations that were delivering the majority of AIDS programming in the country was crucial. This was considered as a collaborative approach that would provide the potential to reach a much larger number of people and would further facilitate access to services for all vulnerable populations, including people with disabilities. According to a recent report¹⁹, the US Government is the biggest financial contributor to AIDS

programming in developing countries, hence the importance of specifically targeting mainstream US-funded AIDS organisations to incite them to be more inclusive of people with disabilities, as this would have an exponential impact on access to and coverage of services.

A

Description of the context before the practice

Prior to this innovative project, very few structured HIV and AIDS projects had people with disabilities as their main end beneficiaries. On the other hand, numerous US-funded and other projects were providing HIV-related prevention and services to a range of at-risk populations, such as female sex workers, mobile populations, uniformed personnel, truck drivers and vulnerable groups such as women and young people. However, people with disabilities were not included in these initiatives despite representing around 17.6%²⁰ of the population (or 14,784,000 out of 84 million people), making people with disabilities one of the largest forgotten minorities and vulnerable groups in Ethiopia.

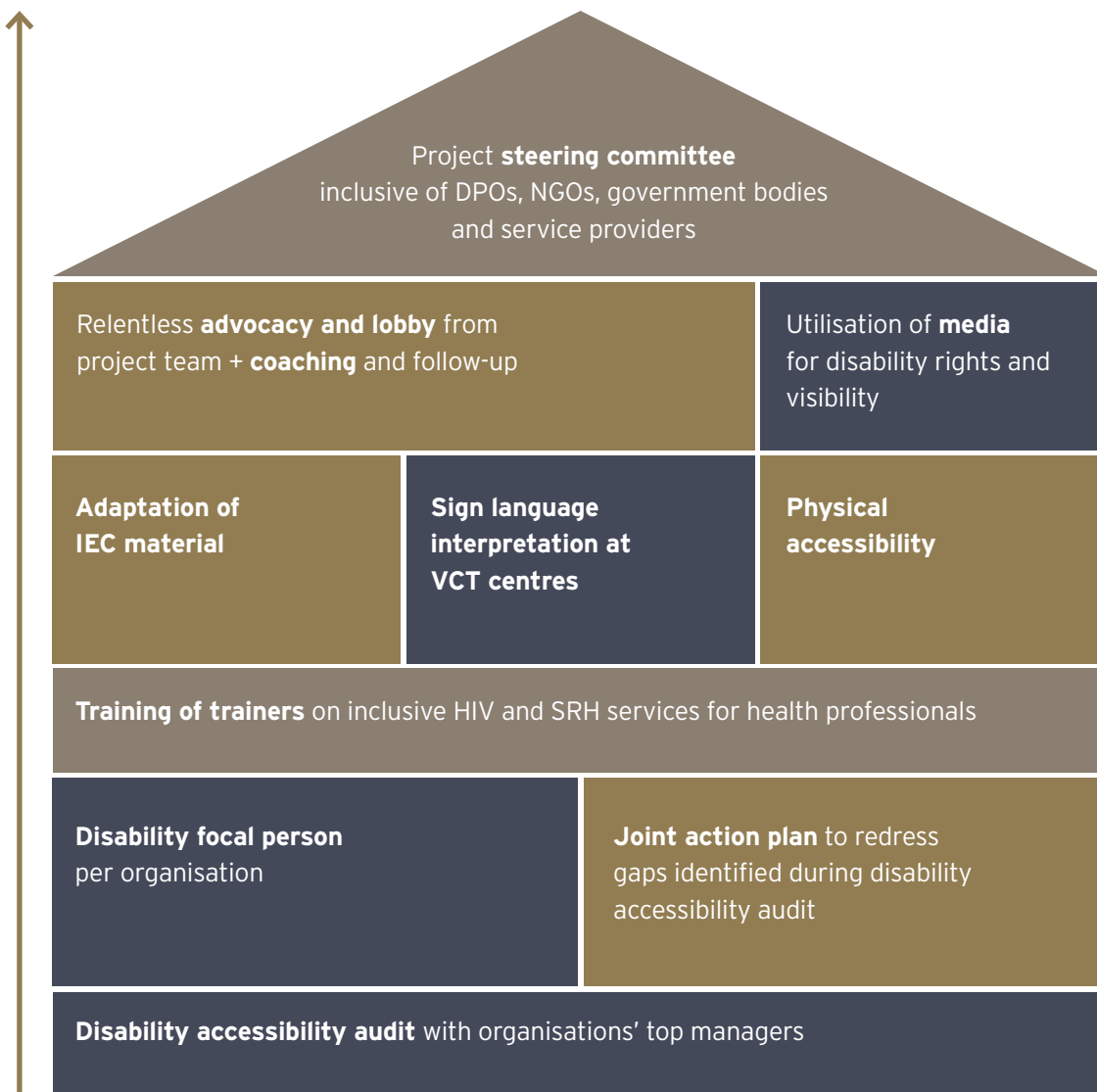
Furthermore, although DPOs did exist, they were not organised to promote the HIV-related rights of people with disabilities with regard to access to HIV prevention services and protection from sexual violence, stigma and discrimination²¹. People with disabilities had been totally overlooked in the previous NSP (2004–2008), revealing a substantial lack of awareness and knowledge of disability issues among AIDS policy-makers and programmers. At both the national and community levels, disability was omitted from HIV policy and service provision, and reasonable adjustments and universal design were not promoted.

B

Description of the good practice

This example of good practice involved a series of strategies and activities that led to the mainstreaming of disability issues by US-funded AIDS organisations and projects. The first stage in this process consisted in organising a disability accessibility audit with

the organisations' top managers, the results of which would provide the starting point for a joint project on accessibility. Indeed, as a consequence of this audit, all the key stakeholders, i.e. each organisation, their partners and the project team, were made aware of the absence of disability inclusion at physical, communication, products, services, M&E and human resources levels. Consequently other activities were implemented in a logical order so as to reinforce disability mainstreaming.



Good practices

Figure 3—Activities implemented in a logical order to reinforce disability mainstreaming

Initiative 2

The results of the disability accessibility audit in which the top decision-makers of each organisation had participated led to all of these organisations appointing a member of their key staff as their disability focal person, i.e. their “in-house” driver of disability inclusion. The next step in the process was to design a joint action plan with all the participating organisations aimed at finding ways to reduce the barriers to HIV prevention and services for people with disabilities within each organisation, according to the budget and time available to them. The specificity of this project was that it didn't stop at showing mainstream AIDS organisations the importance of recognising people with disabilities as a vulnerable group; it also got them thinking about how to improve overall access of vulnerable groups to the services they delivered.

An 8-day training of trainers course for health professionals on inclusive HIV and sexual and reproductive health (SRH) services was organised to improve their practical understanding of disability inclusion, providing concrete knowledge and skills that could be rapidly implemented. This was combined with regular follow-up and coaching of project team members. Depending on their priorities and the focus of their programme, some organisations decided to adapt IEC material to make it accessible to people with different disabilities, including hearing and visual impairments; others chose to improve physical accessibility for people with reduced mobility and older people; and while other organisations decided to become part of a pool of VCT counsellors to learn basic Amharic sign language. All these measures received close technical support from Handicap International and collaborating DPOs. Advocacy activities and coaching were also necessary to maintain both cognitive and behavioural change. Harnessing the power of the media and journalists was instrumental in helping to educate and raise awareness of the wider public on the rights of women, men and children with disabilities with regard to HIV prevention and services.

To oversee all the above-mentioned activities, a multi-stakeholder steering committee was put in place, whose role was to promote the increased inclusion of people with disabilities to HIV prevention and services at all stages of the project. It was composed of all the disability focal people from all the partner organisations, as well as DPOs, disabled representatives of the Bureau of Social Affairs, health professionals and members of Handicap International's team. The committee's ownership of the project and motivation were strong, and proved to be of precious assistance during the translation into Amharic of the Training of Trainers handbook by ensuring the use of culturally-sensitive wording.

C

Most significant changes

Some of the most significant changes to come out of this project are highlighted below. They are embedded in the continuum of HIV care and services and sustained by the partnering organisations and health facilities.

- **Accessibility in VCT services:** The Minelik Referral Hospital, implementing partner of John Hopkins University–Tsehai project, hired two disabled sign language counselors at its VCT and ART centres to provide services for people with hearing impairments. In order to take the disability of incoming clients into account, the VCT data collection tool was updated to include the type of disability in addition to the usual basic information on sex, age, etc. Ramps were also built outside the VCT and ART centres to improve accessibility to services for all.
- **HIV testing and counselling of people with disabilities:** Although the project directly focused on the capacity-building of organisations, more than one thousand people with disabilities (cross-impairments) benefitted from the improved accessibility

of the VCT services (support to peer educators, sight guides, sign language) and disability-friendly VCT counselling, allowing the timely referral of those infected by HIV to care clinics to receive treatment and support services.

- **Partnership with PSI to include disability in their USAID-funded HIV prevention project:** During the implementation of the pilot project, the core activities were awareness-raising and capacity-building. As a result of these activities, organisations such as PSI recognised the strategic importance of working with organisations such as Handicap International to help develop accessibility and disability-sensitive and -friendly services. Thus PSI asked Handicap International to be part of a consortium that applied for a USAID grant for a national HIV prevention initiative. This consortium was subsequently awarded the grant, providing the opportunity for Handicap International to support PSI in mainstreaming disability at all levels of project implementation. This consisted in disability accessibility audits, the training of human resources and partners, discussions on action plans, the development of training material, the preparation of more inclusive IEC and BCC material and products, work on monitoring and evaluation tools, and the development of more disability-sensitive and -friendly services. The project has thus shown that it can be scaled up and extended beyond the capital to reach organisations and health providers in all the country's major cities.
- **Girls with disabilities targeted by Population Council in their ongoing project on vulnerable populations:** Following their participation in the training of trainers course for health professionals on disability inclusion in HIV and SRH services and a series of awareness-raising activities by Handicap International, Population Council decided to revise its training manual for mentors to include a specific section on "Women and Disability", calling on the technical

support of Handicap International's pilot project team. This training manual, covering various topics such as life skills, HIV prevention and gender-based violence, was thereafter used by more than 200 mentors to reach 10,000 vulnerable girls in 18 cities and towns, including Addis Ababa. Furthermore, Population Council scaled up its HIV prevention efforts by setting a new objective specifically targeting 200 girls with disabilities in their *Biruh Tesfa* project and a new partnership with Gemini Trust to teach girls with disabilities to dance.

- **Inclusion of people with disabilities in the current NSP:** Part of the pilot project's work was to deploy efforts to persuade the National AIDS Council to include people with disabilities in different sections of the NSP. During the drafting of the 2010/11–2014/15 NSP, Handicap International was invited to provide technical support to the process. Consequently people with disabilities were successfully included in the NSP for the first time in Ethiopia. Disability issues were taken into account in the following NSP sections: capacity-building, HIV prevention including HIV testing and counselling, prevention of mother to child transmission, STI prevention and services, care and support services, and in the results matrices.
- **Accessibility and disability visibility during the 16th International Conference on AIDS and STIs in Africa (ICASA):** One of the project's specific objectives from the onset was ensuring the inclusion of disability at the 16th International Conference on AIDS and STIs in Africa (ICASA) held in Addis Ababa in December 2011²². After more than a year of work advocating for disability inclusion and visibility, Handicap International, as one of the official members of the ICASA International Steering Committee and in collaboration with its local DPO partners and international partners such as UNAIDS and HEARD, was able to organise two non-abstract driven sessions on the intersection of HIV and disability, with keynote speakers such as Dr Paul

Initiative 2

De Lay, Deputy Executive Director of UNAIDS; a dynamic Disability Networking Zone with a four-day programme; a disability accessibility audit of the venue and conference facilities; and a pre-ICASA conference with more than 30 stakeholders (including DPOs and implementing partners from Sub-Saharan countries) to select at least 15 key mainstream sessions (on HIV prevention, PMTCT, vulnerable populations, sexual and reproductive health and care and support services) where questions on disability inclusion gaps were systematically posed to panel speakers to raise their awareness about the inclusion (and exclusion) of people with disabilities in their current programming.

D

Impact statements

- **From Desta Debalkie, Environmental Health and Sanitation Coordinator at Minelik Referral Hospital:** “The management and health professionals at Minelik Referral Hospital gave no particular consideration to the needs of people with disabilities. I can say that there was some understanding of disability issues among the staff. But no efforts were made to mainstream disability in our services. There are a number of important things that the hospital gained from its partnership with Handicap International... I believe that of all our achievements, the most important is the behavioural and attitude changes I noticed among the health workers after they participated in the disability awareness-raising training organised by Handicap International. But I have also noticed that we still need to work on the management, especially on commitment issues. The efforts of the nurses and other health workers can only be effective and sustainable if they are

backed up by management. Ramps have been constructed in the laboratory, ART and VCT clinics and registration area. Accessible IEC materials and Training of Trainers manuals have been made available by Handicap International.”

- **From Tsehay, a young blind woman:**

Tsehay lives with her big family of two brothers and six sisters. She became blind a year ago. She was brought by her aunt to Addis Ababa to seek medical help. It was during this period that a peer educator from Handicap International visited her at her aunt's house. “Before the peer educator taught me about HIV and AIDS, I did not have any information about it and I also never thought that my disability could make me vulnerable to HIV. I did not know that blind women had a high chance of getting raped. I am happy that I checked my HIV status. It will help me protect myself. I will also tell other people with disabilities where the services are available.”

E

Facilitating factors that made this practice successful

- **Inclusion of people with disabilities in the programming:** People with disabilities were asked for their views on the adaptation of the project's IEC/BCC material, the construction of ramps, and in the hiring of counsellors who could sign or directly as volunteers in sign language training.
- **Ownership by the steering committee:** The project steering committee was not only made up of various stakeholders (government, NGOs, civil society), but also of both disabled and non-disabled representatives. This coming together of two different “worlds” was very profitable and enhanced their understanding of each other's needs and abilities when working towards a common goal.

- **Strong involvement of DPOs and their representatives in governmental posts:**

Cross-impairment DPOs played a crucial role during the project implementation by bringing the strategic views of people with different disabilities, their needs and the programmatic weaknesses of HIV programming to their constituencies. They also encouraged women, men and young people with disabilities to go and get tested. Their disabled peer educators supported this process, building the confidence and awareness of people with disabilities about different aspects of HIV prevention. Furthermore disabled government representatives reaffirmed the importance of working with and for people with disabilities at policy and programming levels.

- **Buy-in by the PEPFAR Coordinator in Ethiopia:** The PEPFAR country coordinator was one of the biggest allies and most fervent champions of this project among PEPFAR's and USAID's entourage. She helped get the project started by sending out official invitations and support letters to all American-funded AIDS organisations emphasising the importance of including people with disabilities among their vulnerable groups. As a result, six US-funded AIDS organisations signed up for the challenge.

- **Tireless advocacy on the part of the project manager and his team for the inclusion of disability issues in HIV policy and programming:** The quality of the project team's endeavours is not to be underestimated. They play a crucial role either as a facilitating factor or as an obstacle to change. The selection of the project manager and his team was instrumental in the project's success. Furthermore, coaching partnering organisations led to the emergence of a more solid foundation for replication and scaling-up initiatives.

F

Barriers or challenges

- **No epidemiological data on people with disabilities at risk of HIV:** One of the main barriers to not having more inclusive HIV projects in Ethiopia is the absence of epidemiological data demonstrating the vulnerability to HIV infection of people with disabilities. Although a handful of qualitative and knowledge, attitudes and practices surveys have been conducted in the country, no hard quantitative evidence has been generated on seroprevalence among people with disabilities in Ethiopia. As national HIV policies and programming have not prioritised the inclusion of disability, no financial resources have been sought and/or allocated to generate such evidence. The lack of this type of crucial evidence is a considerable barrier to achieving accessible HIV services for people with disabilities.

- **No inclusion of disability in the NSP in effect at the time of the project implementation:** One of the first consequences of the lack of more quantitative evidence was the omission of people with disabilities from the NSP and so their exclusion from HIV prevention, treatment, care and support services. This omission drastically reduced the likelihood of technical, financial and time resources being invested in disability inclusion. As this was the national guidance document setting forth the priorities, target groups and resource allocations, not including people with disabilities as a key/vulnerable population sent a signal that they were not worth devoting resources to.

- **Limited financial resources:** The lack of investment on quantitative research and data collection incorporating disability perpetuates the vicious circle of not prioritising disability inclusion. If investments were made, it would provide policy and decision makers with the

Initiative 2

evidence they need to make informed programming choices that could address the needs and close the gaps encountered by people with disabilities.

G

Analysis

Despite limited resources for implementing this project (less than 350,000 USD for 32 months), substantial results were achieved over a relatively short period of time. This shows the effectiveness and efficiency of this type of project focused on capacity building, skills transfer and ownership by top management based on a self-assessment of their own organisational shortcomings in reaching vulnerable groups such as people with disabilities. There is also clear potential for scaling up these activities. Before the end of the pilot project, its core capacity-building plan had been replicated by PSI in their winning consortium project bid on HIV prevention covering all major hubs and cities in Ethiopia. As far as disabled users are concerned, the project has left accessible VCT centres with trained key VCT personnel providing sustainable disability-friendly services. Furthermore, the inclusion of disability issues in the new NSP is the result of practice-based advocacy at all stages of project implementation and provides a strategic orientation that will encourage future national-based projects to also take the needs of people with disabilities into consideration in their HIV prevention, care and treatment services, as well as in their monitoring and evaluation mechanisms. Many of the project stakeholders, including the government, had not understood the urgency of taking into account the 17.6% of Ethiopia's population living with a disability²³—or approximately 14,784,000 people also at risk of HIV infection due to lack of accessible services, lack of skills of health/HIV service providers to deliver

disability sensitive services and non-inclusive policy frameworks. All this is beginning to change due to the seeds planted by the pilot project, paving the way for larger-scale and organised projects specifically focusing on people with disabilities and/or mainstreaming disability into national and regional HIV initiatives.

H

Recommendations for HIV and AIDS practitioners

The key recommendations related to this good practice are as follows:

- If financial resources are available from the start, plan for a seroprevalence study combined with a KAP survey among people with disabilities in key cities or in other regions where HIV prevalence is particularly high in order to have the necessary baseline data on the level of risks and vulnerability faced by people with disabilities with regard to HIV infection.
- Plan a parallel component with a specific expected result and indicators related to improving the capacity of decision-makers in the national AIDS council and related bureaus to include disability in the NSP.
- Add a complementary component to foster the participation of users, i.e. people with disabilities and their DPO representatives, as their involvement and input are essential for increasing the utilisation of accessible HIV services and making sure the voice of the disabled community is heard.
- Systematically undertake a joint disability accessibility audit with the top managers of selected partners, especially when financial resources are limited, in order to get an early commitment on their part to improving the access situation of a group that their organisation may well have overlooked.

- Work with monitoring and evaluation/ statistics teams on how to effectively integrate disability questions/aspects into data collection tools and mechanisms so as to include people with disabilities among total beneficiaries.
- Always ensure that the disability focal person assigned to work on disability inclusion issues has been designated by the organisation itself. This will increase ownership and motivate organisations/ health facilities to bring about changes.
- Budget for sufficiently-qualified project personnel capable of carrying out capacity- building, mentoring, monitoring and evaluation and coaching activities in order to provide tailored services for target organisations and HIV related facilities. Human resources are a key factor in the success or failure of any project.

Initiative 3

Strengthening the role of disabled people's organisations in the HIV response in Rwanda

This example of good practice concerns a key component of a project on “Strengthening communities to integrate people with disabilities in the HIV and AIDS response in Rwanda”, implemented from June 2008 to May 2013 with the financial support of PEPFAR/Health Resources and Services Administration (HRSA)/New Partner Initiative (NPI) and technical support from John Snow Inc. (JSI). The main objective of the project was to reinforce the organisational, managerial and technical capacity of local communities to provide quality HIV prevention and care services to people with disabilities. By the end of the project, 93,393 people with disabilities (57% women) and 246,100 community members (69% women) had received awareness-raising on HIV prevention; 2,090 people with disabilities living with HIV (61% women) had received care and treatment services; 4,903 people with disabilities (54% women) and 8,715 community members had been sensitized on sexual and gender-based violence (SGBV); 53 people with disabilities (56% women) had received SGBV care and treatment services; and nine DPOs and CBOs had benefited from organisational development strengthening. The good practices used in this project are evidence that creating awareness among target populations to the need to include people with disabilities is crucial to bringing about behaviour changes. Equally important is the institutional capacity-building of their representative organisations. In this project, strengthening the organisational development capacities of DPOs and CBOs helped them to mobilise financial resources and increase their institutional credibility

Good
practices

Initiative 3

vis-à-vis donors and also government decision-makers. Strengthening the capacities of these civil society organisations was seen to be essential to enabling them to better promote and defend the rights and needs of people with disabilities and other highly marginalised populations.

A

Description of the context before the practice

In Rwanda, most civil society organisations (CSOs) are relatively recent. The first ones were formed in the 1970s and 1980s and then underwent major changes and restructuring in the 1990s and early 2000s. In the field of HIV and AIDS, CSOs are active, organised and represented in networks and associations such as the Umbrella of Persons with Disabilities in the Fight against HIV and AIDS in Rwanda (UPHLS), established in 2006 with the support of Handicap International and the former National AIDS Control.

At the start of the project in 2008, CSOs were already working in the fields of HIV and AIDS and disability, but their access to funding was limited, their institutional capacity was weak, their coordination was poor and interactions with line agencies were irregular. The project, which covered 16 of Rwanda's 30 districts, was the first-ever large-scale and structured attempt at providing technical and financial support to DPOs and CBOs to strengthen their capacity and ensure their role in HIV prevention and care for people with disabilities. At the time, disability was beginning to emerge as an issue in the 2009–2012NSP, with some of its sections mentioning the vulnerability of people with disabilities to HIV.

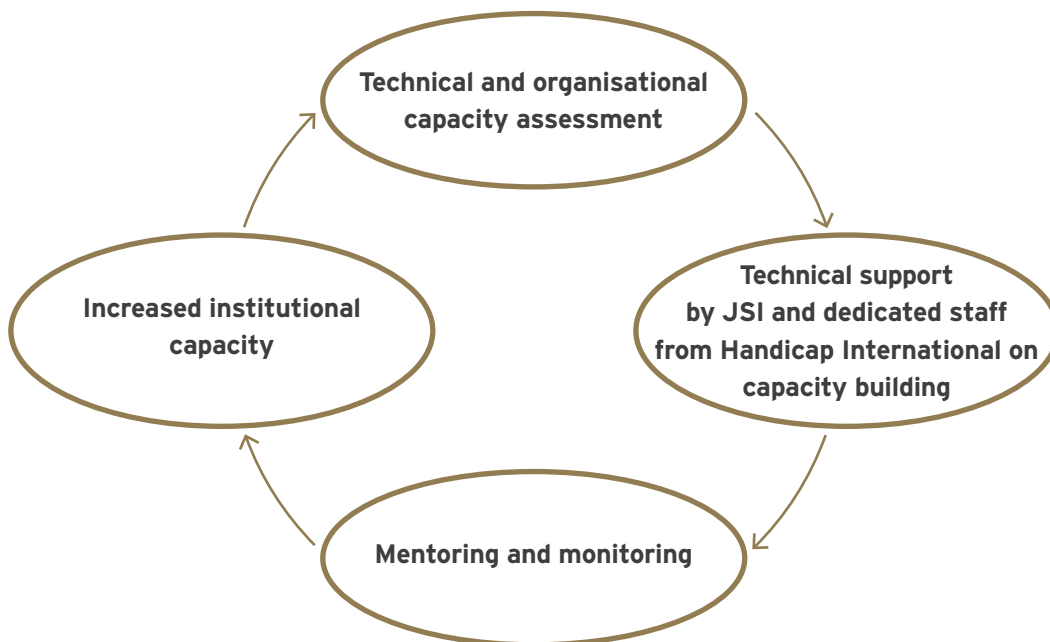
B

Description of the good practice

Most of the project's activities were implemented by nine sub-grantees (UPHLS, four DPOs and four CBOs²⁴). As a newly-founded umbrella organisation whose mandate was to "empower DPOs based on identified specific needs such as capacity-building, planning, advocacy, coordination and the monitoring and evaluation of HIV/AIDS programme activities with regard to the needs of people with disabilities", UPHLS was chosen by the project to act as the coordinator, so that by the end of the project it would have the capacity to fulfill this mandate.

The process of organisational development strengthening was initially provided by JSI to local DPOs and CBOS, as well as to Handicap International's office managers. Technical and organisational capacity assessments (TCA and OCA) were undertaken for each local partner in order to obtain baseline data; this was followed by regular coaching from Handicap International. The areas covered by the TCA tool were HIV prevention, HIV counselling and testing (HCT), prevention of mother to child transmission (PMTCT), care and treatment, and orphans and vulnerable children (OVC). The areas covered by the OCA tool were governance, administration, human resources management, organisational management, financial management, programme management, and project performance management. The organisational capacity-building process used for this key component of the project is illustrated in Figure 4.

Figure 4—The organisational capacity-building process used for this key component of the project



The assessment process was repeated each year with all the partner DPOs and CBOs to measure the extent to which the capacity-building and mentoring activities implemented were bearing fruit. For most of them, the scores achieved in the OCA and TCA subsets improved from one year to the next thanks to regular monitoring visits, troubleshooting meetings, and tailored mentoring activities such as in-person meetings. Additionally, specific examples and training from Handicap International’s professional teams were provided to help partners deal with emerging issues on administrative and financial management, monitoring and evaluation and disability inclusion in HIV programming. Monthly action plans were drawn up jointly and monitored by Handicap International.

C

Most significant changes

Here are some of the most significant changes to have resulted from the organisational development process:

- **Improved capacity to mobilise**

resources: With structured technical and financial support, local partners were able to hire more staff to work on specific tasks instead of all staff working on different tasks at the same time. Training on proposal writing and resource mobilisation enabled DPOs and CBOs to plan project proposals ahead of time and in accordance with donors’ requirements using their newly acquired skills. The funding obtained from the Global Fund for UPHLS’ and AGHR’s projects on HIV prevention for people with disabilities was one of the project’s biggest success stories given that only a few years previously these two local organisations did not know how to write a proposal and did not have the funding

Initiative 3

they needed to meet their organisational objectives.

- **Increased capacity to reach out to people with disabilities on HIV and sexual violence prevention:** Partnering with local DPOs and CBOs knowledgeable of their grass-roots networks was instrumental in scaling up the mobilisation of people with disabilities and vulnerable groups at the community level. Capacity-building on planning and monitoring and evaluation also influenced the way DPOs and CBOs interacted with their constituency. Because DPOs and CBOs were the direct implementers of project activities, stronger links were developed with the community.
- **Increased coordination of DPOs in the national HIV response:** With additional training on leadership, coordination and advocacy, partner DPOs gradually became credible actors in the promotion of the rights of people with disabilities in HIV policy and programming at the national level. With on-going support from the project, this credibility became evident when UPHLS was able to fulfill its mandate of coordinating the needs of people with disabilities and addressing HIV programmatic disability-related gaps with the Rwandan Biomedical Centre's HIV department/Ministry of Health.

HIV and AIDS. So for anything related to people with disabilities and HIV and AIDS, people come to us to ask what they can do". She also added: "... we were empowered because we received a lot of training on monitoring, referrals, communication, disability and planning. By the end of the project, the organisation was able to draft many project proposals and some of them were successful. And I think, if I may say so, the "Global Fund project" that we have now is one of the fruits, results, of the NPI/Handicap International project".

- **From Marie Anita Ahayo, Director of Injuries and Disability Unit and former VCT Coordinator at the HIV Division, MoH/Rwanda Biomedical Centre (RBC):** "... Among the things to come out of our collaboration with UPHLS, thanks to the NPI/Handicap International project, are the adaptation of existing IEC material to meet the needs of people with disabilities, the training of health professionals and advocacy for ensuring the inclusion of disability in all the components of the new NSP 2013–2017. I was also able to attend the international conference on HIV and disability in Kigali supported by Handicap International, UPHLS, UNAIDS and the Ministry of Health... I am very committed to working with partners like Handicap International and others. People with disabilities are among the country's priorities in its vision for 2020."

D

Impact statements

- **From Mathilde Umuraza, programme manager, UPHLS:** "To begin with, our office was headed by only one person. Because of the project, we grew to be six people. Now (in 2013) we have over 20 staff. Our organisation also gained recognition thanks to the project. Everybody now recognises that UPHLS is an organisation working specifically for people with disabilities in the field of

E

Facilitating factors that made this practice successful

- **Appropriate project planning and budgeting for organisational development from the project design stage:** This might seem obvious, but in fact the organisational development of local partners is very often overlooked

when building strategic partnerships. With a specific objective of building the organisational, managerial and technical capacity of local organisations, this project planned specific human resources and training activities as part of the inputs, as well as a corresponding budget for implementing these activities. Furthermore, the technical support from JSI as part of the New Partner Initiative was well thought-out as it recognised the importance of ensuring organisational strength before actually implementing project activities. This strategy was beneficial for all partnering DPOs and CBOs whose institutional capacities were not sufficiently developed to allow them to effectively promote and defend the rights of their constituency. Through this capacity-building and process-oriented intervention, several partners were able to substantially strengthen their capacities by the end of the project.

- **Regular re-assessment of partner's organisational capacity and mentoring:** The annual re-assessment by the project and follow-up by JSI were instrumental in maintaining the momentum by not only contributing towards building the capacities of DPOs and CBOs but also by helping to build bridges between the project's objectives and their organisational mandates. The regular reassessments served as a constant reminder of and motivation for achieving their ultimate goal. Furthermore, the mentoring provided by the project team in charge of capacity-building helped identify areas to be included in subsequent training plans. The training plans were based on the partners' identified training needs and their expressed needs for more capacity building.
- **Eagerness to learn more about disability on the part of all project stakeholders:** Among all the project stakeholders, i.e. community members, DPO/CBO members, government officials and health workers, there was an eagerness to learn about the needs of people with disabilities with regard to HIV and AIDS prevention,

treatment and care. This willingness to change perspectives was helped by direct contact with people with disabilities, with the inclusion of DPO staff and people with disabilities in discussion groups, district and national meetings and training sessions. These opportunities empowered people with disabilities and gave them an opportunity to make their voices heard, especially at the national level during technical HIV committees or platforms.

F

Barriers or challenges

- **Simultaneous implementation of organisational development processes and project activities:** One of the difficulties expressed by project partners was creating a balance between institutional capacity-building activities and activities implementation. The project's initial duration (three years) was considered too short for building the institutional and technical capacity and also implementing activities. Organisational capacity development was also affected by the precarious financial position of some of the partners at the start of the project. The HRSA subsequently extended the project by two years, allowing actors and partners more time to learn and implement what was planned, with additional interventions in year 4 and 5 on sexual and gender-based violence (SGBV) prevention and care.
- **Short implementation period for consolidating DPOs' and CBOs' institutional development:** Although many DPOs and CBOs made notable progress in their organisational development between the beginning and the end of the project, they commented that additional years focusing only on institutional development would have been welcome, accompanied by even

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more in-depth training on some of the organisational development subsets. They felt that learning at a more reasonable pace and within a more reasonable timeframe would have produced better results.

- **Large number of DPOs and CBOs to train and support:** Another difficulty observed by partners and project members was the large number of partners (9) of varying sizes and scopes of activity considering the initially limited capacities of partners and the time and funding available. Both partners and project target populations had very high expectations of the project as this was the first large-scale initiative on HIV and SGBV targeting people with disabilities in Rwanda. Support to partners could have been spread out more over the first few months to allow more time for each DPO and CBO to come to terms with what they were learning.

add to the quality of the overall project but it also sends a strong message that capacity building of and with partners is essential to project effectiveness, efficiency and sustainability.

For instance, this strategy enabled two key DPOs in Rwanda, UPHLS and AGHR, to obtain a Global Fund grant thanks to their newly acquired skills and their ability to demonstrate their added-value, to advocate for the rights of people with disabilities in the response to HIV and to propose accessible HIV prevention and care services to women and men with different impairments who are vulnerable to the infection. Furthermore, the organisational development of DPOs enabled them to credibly represent people with disabilities at the national policy and dialogue level. More specifically, UPHLS has since been systematically invited to provide its expert opinion on the inclusion of disability issues in HIV policy and programming in Rwanda. From a sustainability perspective, by assisting local organisations to serve and represent their own constituency so that vulnerable populations have better access to HIV prevention and care, capacity-building is perhaps one of the most important long-lasting strategies. Furthermore, strengthening the capacity of organisations and their personnel empowers the community to address local challenges and find local solutions to local needs.

G

Analysis

This project demonstrated that very interesting programme results, such as mobilising new financial resources, can be achieved when plans for the organisational development of local CSOs are built into the project implementation framework. All too often in international development, project developers put too much emphasis on the implementation of activities in order to reach a set of outputs within a specific period of time and not enough on the quality of inputs. Yet achieving these outputs is very much dependent on the quality of the inputs, and the capacity of partners is paramount to a project's success and/or failure to achieve expected results. As demonstrated by this project, when partners have both the technical and organisational capacity to achieve expected results, not only does this

H

Recommendations for HIV and AIDS practitioners

The key recommendations related to this good practice are as follows:

- To systematically assess the organisational capacity of local CSOs and plan for structured institutional development-building that is fully supported technically and financially throughout the entire project. Ideally, capacity-building should

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Disability-sensitive HIV information and services for people with visual impairments in Kenya

take place before the start of project implementation, as this could be too much for partners, if conducted simultaneously.

- This training should gradually be scaled down to grass-roots level only so that the capacity-building can then be implemented by the DPOs and CBOs already trained. Using this model, skills, lessons learned and success/failure stories can be retained within the sector and within communities.
- To systematically plan and budget for coaching and mentoring activities and allocate additional staff to work exclusively on providing technical support to DPOs and CBOs.
- To organise annual review and planning workshops/events with all DPOs and CBOs to foster exchanges on barriers and solutions for observational learning, peer support and community empowerment.
- To explore the use of available tools to monitor and evaluate the organisational capacity development processes. As an example, mHealth might be used in the future to encourage local organisations to start using mobile technologies to extend their reach to people with different sensory impairments. Many people with hearing and visual impairments rely heavily on their mobile phones to receive information and communicate with others. Use of new tools such as mHealth might further strengthen DPOs' and CBOs' support to their constituency in obtaining universal access to HIV prevention messages and care.

This example of good practice concerns a project that focused on increasing access to HIV information and services for people with visual impairments in Kenya. The project was implemented in the region of Nairobi in 2012 and funded by the Government of Kenya/World Bank through the "Total War against AIDS" national programme. The main objectives of the project were to: 1) adapt, produce and disseminate patient education/literacy and awareness materials on sexually transmitted infection (STIs), tuberculosis (TB) and HIV care and treatment in accessible formats for, and 2) create awareness on STIs and HIV related information, knowledge and services among people with visual impairments in Nairobi, Kiambu and Machakos. This initiative specifically targeted people with visual impairments in order to remove communication barriers and enable them to access disability-sensitive health and HIV related information and services.

A

Description of the context before the practice

The Kenya Demographic and Health Survey 2008/09 in effect prior to the introduction of this good practice revealed an HIV prevalence of 6.4% among Kenyan adults aged 15–49 years. However, HIV prevalence among people with disabilities was not established due to the absence of inclusive

Initiative 4

indicators in the survey, as well as a lack of inclusive programming that excluded people with disabilities from the national AIDS response. According to one of the rare knowledge, attitudes and practice (KAP) assessments undertaken among people with disabilities²⁵ in Kenya, 11% of people with visual impairments, 20% people with hearing impairments and 14% people with physical impairments who were sexually active reported having multiple partners over the six months preceding the survey. The survey also found that people with disabilities engaged in substance abuse, an activity closely linked to risky sexual behaviours and HIV. The survey further revealed that among people with visual impairments only 40% had knowledge of HIV and 36% of condom use, and the voluntary counselling and testing uptake was only 34%. These percentages were relatively low compared to people with other types of impairments.

Furthermore, the Kenyan National AIDS Strategic Plan of that period did not inclusively integrate people with disabilities in its prevention, treatment, care and support services, nor did it include disability in its monitoring and evaluation indicators. On the other hand, Handicap International and various national DPOs in the region of Nairobi and in the Rift Valley were already providing HIV related information, prevention and services to people with different impairments with the help of funding from AIDS, Population and Health Integrated Assistance (APHIA) I and APHIA II. Although HIV-related information was disability-sensitive, not all IEC materials were fully accessible to people with sensory impairments. This example of good practice attempts to specifically address this need for people with visual impairments.

B

Description of the good practice

This good practice started with the setting up of a committee of people with disabilities and their DPO representatives to be part of a consultative body that would be advising and guiding the project in designing IEC material that met the communication needs of people with visual impairments and effectively conveyed HIV related messages to them. Strategic partnerships were forged with Blind and Low Vision Network (BLINK) and Nairobi Family Support Services (NFSS), two long-standing Nairobi-based DPOs with considerable experience of working for and with people with visual impairments.

The involvement of people with disabilities and DPOs in adapting the IEC materials promoted by the Kenyan National AIDS Council in accessible formats for people with sensory impairments was vital for ensuring more targeted interventions. Materials were produced in large print and Braille and audio messaging was used for topics such as HIV prevention; the challenges faced by people with visual impairments in disclosing their HIV status; multiple stigma faced by people with disabilities in relation to HIV; the challenges experienced by people with visual impairments in accessing VCT services; or barriers faced by them while attempting to use ARV as they cannot see to distinguish the different drugs they have to take.

Radio talk shows were also organised so that people with visual impairments as well as non-disabled people could tune in and learn more about HIV, STI and TB. All this was backed up by community mobilisation and awareness-raising by disabled peer educators who also carried out home visits to help people with visual with impairments learn how to use condoms in the privacy of their homes. This enabled them to gain confidence and learn in a confidential environment.

C

Most significant changes

Improved uptake of HIV services:

Handicap International learned from this project experience that packaging health/HIV-related communication messages in accessible and user-friendly formats for people with visual impairments and then disseminating them through peer education significantly improved the uptake of HIV services. As a result, 8,796 people with visual impairments were reached with HIV information on prevention, treatment and care; 23 community discussion sessions were organised; and 3,064 people with visual impairments went for counselling and testing. These results are very revealing, considering that previous data that did not specifically focus on people with visual impairments and HIV-related information pertaining to this group was limited.

D

Impact statements

— **From Pauline Chisaka, community health worker in Nairobi's Kibera slum:** "I provide counselling and promote adherence to treatment in 12 villages in the Kibera slums. Thanks to NFSS supported by Handicap International, I have learned ways of communicating with people with various types of disabilities, especially those with visual impairments, which has allowed me to offer more services to this vulnerable population. These newly developed communication skills, such as adopting a more appropriate and proactive attitude, have really helped me to make my interventions work. The major barrier that I face as a health worker is that most

people with disabilities have not yet been reached with HIV information. This means more time is needed with them to explain the relevant issues, avoid confusion and ensure their needs are met. Ultimately, it is clear that HIV can infect anyone, with or without a disability. I have learned it is important to remember that people with disabilities are human beings with sexual needs and are sexually active. This makes it imperative that they are reached with quality information about HIV prevention and treatment."

— **From Mary Atieno²⁶, a young woman living with HIV and residing in Nairobi's Kibera slum:** "I first learned I was HIV positive when I visited a health facility when I was pregnant in 2008. Since then, I have been living in denial and am troubled by self-stigma. I found it very difficult to accept and come to terms with my HIV positive status. At 22 years old, I became visually impaired as a result of a Meningitis infection, a consequence of HIV. I knew I needed to come to terms with my own diagnosis, and wanted to prevent the same thing happening to others in my community. In Kibera, many people with disabilities and society in general, do not believe that a person with a disability can get infected with HIV. I was desperate to provide more accurate information to my community but did not have the necessary skills or information myself. Fortunately, in 2012 I was chosen to become one of the beneficiaries of training and awareness creation sessions on HIV and AIDS that were conducted by NFSS, with financial support from Handicap International. The training was focused on learning the difference between HIV and AIDS, how to proactively manage HIV/AIDS through positive lifestyle choices such as good nutrition, exercise, safer sex practices, adherence to treatment regimes and how to manage opportunistic infections. The training and awareness sessions conducted by NFSS helped me to overcome denial, and for the first time I was able to disclose my HIV positive status to my close family members and friends.

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Even physically I saw big changes, my CD4 count was 108 before the training, and one year after the training it increased to 859. I have now become a peer educator and leader of Vumilia support group for disabled people based in Kibera. Through this group I am able to reach people with disabilities to provide HIV information and help others to access services. I am also working with health workers to increase their awareness and change their attitudes towards people with disabilities. I encourage all health practitioners to make their health services accessible in order to promote disability inclusion.”

E

Facilitating factors that made this practice successful

- **Specific government funding allocation:** One of the most powerful facilitating factors was the specific funding provided by the Kenyan Government through its National AIDS Council to target people with sensory impairments in its HIV prevention response in recognition of the fact that they are also at risk of HIV infection. This support provided a good foundation for Handicap International's work based on its long experience of disability and HIV and enabled the swift production and dissemination of very large quantities of IEC material in accessible formats for people with visual impairments in the Nairobi region. This significant investment enabled nationally-validated messages on HIV, STI and TB to be adapted for people with different abilities.
- **Strong participation of people with disabilities through DPOs and peer educators:** Another key facilitating factor was the strong member base of both DPO partners and the network of peer educators involved in promoting accessible material and encouraging people with

visual impairments to participate in large numbers and learn from the project. Many of them had heard of HIV, but could not learn properly and adopt safer HIV-related behaviours because of communication barriers. Using different outreach and awareness-creation strategies helped people with disabilities to learn better and obtain information from various sources over the course of the project's implementation.

F

Barriers or challenges

- **Short project implementation period:** The most important challenge for this project was the prescription of a nine-month implementation period imposed by the government. Despite its many achievements, the time factor created an additional stress for the implementers, partners, beneficiaries and their families. Furthermore, for people to adopt healthier behaviours knowledge acquisition is important, but time is also needed for various factors (personal, educational and environmental) within a targeted population to have an effect and sustainably change behaviours. Nor was there sufficient time to evaluate the results of the project or measure clients' satisfaction with the project's communication services.
- **Lack of ongoing financial investment:** Another challenge for this very short project was the lack of ongoing financial investment to pursue the outcomes of awareness-raising efforts with the adapted IEC material and to link these to other HIV-related services in the continuum of care. This may jeopardise the long term sustainability of the results obtained. This is an important issue that all projects and funders should bear in mind; otherwise well-intentioned projects may come to nothing.

G

Recommendations for HIV and AIDS practitioners

The key recommendations related to this good practice are as follows:

- A minimum of a few years is needed for the whole change process, from cognitive to sustainable behavioural change, to occur. This is especially vital for people with disabilities as most HIV-related information and services are not readily available in disability-friendly and accessible formats.
- When designing communication tools and information, it is important to apply the principles of “universal design” so there is no need to adapt materials at a later stage as they are also accessible for ALL from the inception.
- If communication information and materials are not already accessible, it is important to apply the principle of “reasonable accommodation” in order to respond to the different needs of all people, including those with different impairments.
- Budgets for communication tools and projects need to be disability-sensitive so as to target all people, including people with disabilities.
- Design and link awareness-raising on HIV and AIDS directly to service utilisation and evaluation—this is especially important for placing people with disabilities on the same footing as any other HIV and AIDS services users.

Initiative 5

Specific initiative for deaf women and the integration of sexual violence protection in rural areas of Cambodia

The Cambodia programme was the first to integrate HIV prevention and sexual violence protection for people with disabilities into one of Handicap International’s HIV and disability projects. The resulting good practice stems from specific initiatives implemented for deaf women and people with disabilities in two rural provinces of Cambodia.

The Cambodian project was part of a regional initiative that also involved Vietnam and Laos. It was implemented from 2008 to 2012 and was funded by the French Development Agency (AFD). Its main objective was to improve access to HIV and AIDS prevention, care, protection and support systems for people with disabilities, and notably for deaf women in Kampong Cham and Battambang provinces, by strengthening the capacities of existing and emerging disabled people’s organisations. The project used the “twin-track”²⁷ approach to provide support to specific initiatives for empowering people with disabilities/DPOs.

Mainstreaming HIV prevention and sexual violence protection is crucial because, according to a global HIV and disability study, people with disabilities have the same or a higher risk of HIV infection and sexual violence as their non-disabled peers²⁸. A recent report from UNAIDS²⁹ clearly highlighted the intersection of HIV and violence against women and girls: 1) “violence against women is a human rights violation”, 2) “women are 55% more likely to be HIV-positive if they have experienced intimate partner violence”, 3) “women living

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with HIV are more likely to be subjected to violence”, 4) “women most vulnerable to HIV are also most vulnerable to violence”, and 5) “violence undermines the HIV response by creating a barrier to accessing services”.

A

Description of the context before the practice

Other than anecdotal information about women with disabilities experiencing sexual violence and being at risk of HIV infection, there had been no previous data or projects on the intersection of HIV, sexual violence and disability in Cambodia. The law on the Prevention and Control of HIV and AIDS was adopted in 2002 and the national strategic plan for a comprehensive and multi-sector response to HIV and AIDS was revised in 2010. Looking back over the past 15 years, HIV prevalence in Cambodia peaked at 2.6% in 1998 before steadily decreasing to 0.7% in 2013 thanks to innovative HIV prevention efforts, including a comprehensive condom usage programme, voluntary counselling and testing, the PMTCT/Linked Response approach, sexually transmitted infection care, and outreach activities. However, people with disabilities were not included in HIV and AIDS prevention and response efforts. Data collected on sexual violence and rape were limited and unreliable due to stigma and discrimination, fear of retaliation from abusers and their entourage and the markedly low number of non-judgmental and user-friendly multi-sector gender-based violence services. Moreover, data were not properly disaggregated and, needless to say, disability was not captured in reporting.

Given the context and data gaps, in 2007, Handicap International decided to explore the issue of HIV and disability through four participatory learning action (PLA) sessions in Battambang and Kampong Cham.

These PLAs were aimed at identifying the groups of people with disabilities most at risk to HIV infection and sexual violence. Although the level of awareness among people with physical impairments was seen to be congruent with that of the general population, the exercise showed that people with disabilities took more risks when engaged in sexual relationships. In addition, respondents with sensory impairments reported having little or no access to health prevention services and messages. Even more shockingly, the PLAs revealed that 40% of deaf women respondents were survivors of sexual violence and/or of sexual abuse attempts.

B

Description of the good practice

Working in rural communities with deaf women to raise their awareness of HIV, sexual and reproductive health and sexual violence protection was a crucial component of this project. The activities focused on helping deaf women to learn more about HIV and sexual violence prevention and services. A number of key good practices were identified through a participative and longitudinal exercise³⁰, including:

- **Mapping of people with disabilities and in particular, deaf people living in target villages:** This was one of the most crucial inception phase activities undertaken by the project. It was important to identify deaf women, where they were living and their family situation. It was also important to develop close relationships with local authorities such as the councils, village chiefs and school directors before the activities began in order to obtain their support for the action, as this would provide a positive environment at community level and encourage women and their families to participate in the project.

- **Conducting home visits and mobilising local leaders to encourage community 'buy-in'.** Sign language classes and HIV and sexual violence prevention sessions were organised on the commune's premises or in other public places within the community. The fact that these activities were run in the communities where the deaf women lived was very useful for setting follow-up appointments and building trust with parents and families. This strategy also provided an opportunity to raise awareness among the representatives of local bodies and among family members who were also welcome to listen to and attend project activities.
- **Close partnership with the Deaf Development Programme of Maryknoll (DDP) to devise a joint sign language curriculum in Khmer on HIV prevention/sexual violence protection and education.** This strategic partnership and the partners' shared goal of helping deaf women to learn sign language and play a more active role in their community were extremely important in crafting a comprehensive and participatory process that took into consideration the strength and expertise of each partner. Handicap International learned a lot from the DDP on deaf culture and language acquisition among deaf people, and the DDP learned much about rural participatory processes, HIV prevention and sexual violence protection methodologies and tools from Handicap International. Moreover, capturing regular feedback from deaf women, their families and implementing partners improved the quality of project implementation.
- **Training educated deaf women to become future trainers and awareness-raising facilitators for other deaf women.** These newly trained deaf women were paired with a member of Handicap International's staff who had received basic sign language training for coaching and shared learning purposes. Communicating in the same language as deaf women was vital for the project's capacity-building activities and sustainability.

- It was necessary to **teach sign language and related vocabulary** before helping the deaf women to learn about HIV prevention and sexual violence protection. This involved prolonged ground work with the DDP and several piloting phases to produce a glossary of Cambodian sign language. Deaf women and deaf trainers, as well as Handicap International staff who had learned basic Cambodian sign language, provided ongoing feedback for a period of 18 months before HIV prevention and sexual violence protection awareness-raising eventually got underway.
- **Development of visually-friendly IEC material:** The design and utilisation of clear and explicit material supported by the development of Cambodian sign language, including pictures, simple messages and role play as well as guided tours of local services and facilities, greatly facilitated deaf learners' acquisition of knowledge and new skills and gave them a feeling of empowerment.

For further understanding of some of these good practices, readers are invited to view a video documentary on this project at: http://www.youtube.com/watch?gl=FR&v=M_Ar4LSXhgQ and <http://www.youtube.com/watch?v=IDA0VlqQuOQ>

C

Most significant changes

- **Development of a subject-specific set of Cambodian signs:** One of the most significant changes to the project was the intentional delay to the start of the awareness-raising activities. This delay was recommended by the DDP and satisfied Handicap International's aim of delivering a specific quality-based initiative for deaf women in rural Cambodia. The suggestion was to start by providing Cambodian sign language training to deaf women prior

to providing awareness-raising activities. After a certain amount of technical and programmatic exchanges between the DDP and Handicap International in 2008–2009, the decision was taken to postpone the beginning of the awareness raising activities for deaf women in Battambang and Kampong Cham by almost a year.

After the administrative procedures relative to the changes in the action and budget plan had been completed, both partners embarked on an innovative process to develop a common set of Cambodian signs for discussing issues such as HIV prevention, human rights, sexual violence and disability rights. They drew on each other's expertise: deaf culture and sign language for DDP and HIV prevention, sexual violence protection and disability rights for Handicap International. Fortunately at that time, the DDP also had a deaf American PhD candidate, from Gallaudet University, who was fluent in American and Cambodian sign languages among others. The PhD candidate also helped the project adopt a more scientific and process-oriented methodology with the deaf women of Cambodia.

- **Wider impact through joint training of Handicap International health staff and DDP-educated deaf women:** A second significant change was the decision to simultaneously train Handicap International health staff in basic Cambodian sign language and the DDP-educated deaf women to become trainers on health/HIV/sexual violence protection issues identified by Handicap International. This was a win-win situation whereby both partners put emphasis on long-term impact, sustainability and effectiveness as well as short-term efficiency. This programme decision proved to be beneficial to all—in particular to deaf women and their families who were given the opportunity to learn a new language and go through various language acquisition processes.

- **Local ownership of training:** A third significant change was that the DDP took over the delivery of training on HIV and sexual and reproductive health rights and issues for deaf women and men in their language/life skills centres, for instance in Kampong Cham province. This transfer of skills to one of the closest partners was a clear sign of its ownership of the project.

D

Impact statements

- **From Chanthou Sak, young deaf woman:** “Before I felt lonely not knowing sign language. But after receiving training from the four trainers, I feel happy and know a lot. I feel now very glad to learn from them, with many activities. I am happy and they are (women who are deaf) all my friends. People who hear do not like to hang out with me. So most of my friends are people who are deaf. When I come to learn, I meet them. I feel very happy.”
- **From Mr. Chorn Ung, father of a young deaf woman:** “In the beginning my daughter came to learn sign language. Later on, Handicap International taught her about HIV and AIDS. On this course, I noticed her knowledge really improved.”

E

Facilitating factors that made this practice successful

- **Common understanding between partner management teams:** The first facilitating factor of this successful practice was the common understanding established between the DDP's and Handicap International's management at that time;

the ultimate goal of both organisations was for deaf women to be able to learn, be empowered and participate socially by means of an important social skill: language acquisition. This common understanding is what persuaded partners to engage time and technical and financial resources. In 2008–2009 the DDP contributed 20–25% of the cost of sign language classes for deaf women.

- **Mutual recognition of the importance of deaf women learning sign language:** Both the DDP and Handicap International saw it as imperative that deaf women should learn sign language so that they could become autonomous enough to understand HIV prevention, transmission and protection measures on their own, as well as issues concerning disability rights, gender-based violence and life skills. This dedication to the project's cause was instrumental in the decision by the DDP's director, deputy director and technical advisor and Handicap International's staff to work together throughout the process, overcoming one obstacle at a time, in implementing this ground-breaking activity. Regular meetings between the key stakeholders enabled the project to move ahead with consensus, even if at times things went more slowly than expected. This dedication and resource allocation produced results that were more solid, sustainable and relevant to deaf women, their family members and the entire community.
- **Needs of deaf women always remained central:** Each partner was sufficiently flexible and sensitive to the needs of deaf women, their families and the community to adjust the programme's activities accordingly. The partners thus put the needs of these people above the "logistical" realities of the project and went beyond what was written in the project proposal. The overall project objective was respected, but some of the methodologies were modified during implementation to better respond to the needs of people with disabilities and more closely tailor project strategies.

F

Barriers or challenges

- **New focus for the community and organisations involved:** The first challenge lay in the fact that this type of project focusing on HIV and sexual violence prevention for people with disabilities and with a specific focus on deaf women was entirely new to the local community, as well as to the DDP and Handicap International in Cambodia. The partners learned as they went along how to work with one another, understand each other's priorities and work in the best interests of rural deaf women and their relatives. Their success was due to adopting specific strategies such as the mapping of people with disabilities, home visits, the drafting of a programme agreement between the DDP and Handicap International clearly setting out the deliverables expected from both parties, and the design of disability-friendly and -sensitive IEC material and methodologies for deaf women.
- **Lack of national homogeneity in sign language training:** Another significant challenge that led to a number of brainstorming sessions spanning several months was the absence of homogenous sign language training in Cambodia. In 2008, there were only two organisations providing sign language to adult deaf people who training to deaf people: Krusar Tmei taught American sign language to deaf children in four schools in four cities of Cambodia and the DDP taught Cambodian sign language had never attended a school of any kind mainstream, special or school for the deaf. This situation proved to be extremely challenging as the project was targeting people living in the rural areas of the two most populated provinces. To deal with this, and with a view to ensuring sustainability, the pace of the project's

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implementation was deliberately slowed down to enable all partners, especially the deaf women, to take part in the process of developing a glossary of Cambodian signs for HIV prevention, sexual violence protection, disability and human rights. Time was also allowed for trial and error through pilots of various training modules and skills transfer.

- **Lack of universally accessible material:** Coupled with these structural challenges, people with different types of disabilities (also targeted by the project) faced communication barriers. Most IEC materials promoted by both mainstream public and private service providers were not disability-friendly, few people were aware of their existence and they were inaccessible to deaf women. Once a basic sign language training curriculum and prevention and protection materials had been finalised, the teams from Handicap International and the DDP developed a tool box made up of a training curriculum (cross-impairments), flash cards, talking books (for people with visual impairments), radio dramas and three questions-answers facts sheets on HIV prevention and sexual violence.

sound understanding of one another's priorities, needs and issues, and mutual respect for what other partners can bring to the development equation.

- Tailor project activities to the needs of communities, as was done here for deaf women in rural areas of Cambodia. This concern should supersede any administrative or logistical issues related to the project.
- The mapping of potential target populations is of crucial importance and no shortcuts should be taken with communities' needs assessments; this step is vital to the success of the rest of the project implementation.
- As non-disabled or hearing people, do not underestimate the extent/effect of the communication barriers experienced by people with disabilities. For example when a deaf person is acquiring knowledge through communication skills, this enables them to participate in society on an equal basis with others. Helping deaf women learn a language that is suited to their needs, i.e. removing one of their most restrictive communication barriers, was one of the most powerful activities for deaf women to feel happy and connected with their family and others.



G

Recommendations for HIV and AIDS practitioners

The key recommendations related to this good practice are as follows:

- Take whatever time is needed at the beginning of the project to establish a common understanding with the closest and most strategic partners, even if the process is long and painstaking. In the long run, the return on this investment will be an enhanced partnership, a more relevant project, and a high-quality implementation for people with disabilities. A successful partnership is based on a

Initiative 6

Disability-inclusive international AIDS conferences from 2008 to 2014

This good practice of disability-inclusive international AIDS conferences is the result of years of joint collaborative advocacy by members of the International Disability and Development Consortium's³¹ Task Group on HIV and Disability to ensure that disability and people with disabilities are on the agenda of international AIDS conferences. The success stories recounted in this section specifically concern experiences between 2008 to 2014 in Sub-Saharan Africa and the North.

Including disability in international AIDS conferences is crucial for the world's one billion people living with a disability. At events such as these, where scientific developments are disseminated, advocacy initiatives promoted and strategic networking developed, thousands of practitioners, clinicians, academics, researchers, activists, decision-makers and donors, convene to share their HIV-related know-how and learn from the wider community about emerging trends, knowledge and skills. This therefore offers a great opportunity to reach a large numbers of AIDS decision-makers and implementers and stress the importance of including 15% of the world's population. Not doing so will make inclusive post-2015 MDG goals and universal access little more than a pipe dream.

A

Description of the context before the practice

Every year, a number of international, regional and national AIDS conferences are organised. Among these conferences are two very important ones: 1) the International AIDS Conference (IAC), which is held in July every two years and deals with global issues related to HIV and AIDS; and 2) the International Conference on AIDS and STIs in Africa (ICASA), which is also held every two years in December and focuses on HIV and AIDS in Africa, the most HIV-stricken region in the world. Incidentally, these two conferences are held on alternative years so there are no competing demands on availability, time or resources for each conference.

More specifically, the 17th IAC was held in Mexico in 2008; the 15th ICASA in Senegal in 2008; 18th IAC in 2010 in Vienna, Austria; the 16th ICASA in 2011 in Addis Ababa, Ethiopia; the 19th IAC in 2012 in Washington DC, USA; the 17th ICASA in 2013 in Cape Town, South Africa; and the 20th IAC in 2014 in Melbourne, Australia. Each conference has an international steering committee (ISC), a conference organising committee and various technical committees (scientific, leadership and community programmes). Usually once one conference is over, 18 months prior to the next one, there is a great deal of activity on the part of international and national stakeholders to decide on the conference programme, the list of speakers, the selection of scientifically sound abstracts, the thematic areas to be covered and the resources required. This whole period, especially the final six months leading up to the AIDS conference, are filled with discussions to determine which topics will be included. For the disability community, it is a hectic and energy-consuming time, as it involves numerous exchanges and much

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follow-up and preparatory work to keep disability inclusion and accessibility issues both visible and sufficiently high up on the conference's agenda.

Before the coming together of a number of like-minded organisations under the Africa Campaign on Disability and HIV and AIDS³² from 2007–2011, which advocated for disability mainstreaming at various levels, including in policies, programming, research and international AIDS conferences, the HIV-related rights of people with disabilities were not addressed at international AIDS conferences. Disability was completely overlooked and, worse still, rendered invisible. There were only a handful of social scientists and activists working separately on the intersection of disability and HIV. There was therefore a need for an exchange and advocacy network to move issues of disability and HIV forward. At the IAC in 2008 a small disability booth was set up by a US-based scientist (Leila Monaghan). Together with representatives from the Africa Campaign on Disability and HIV (Jill Hanass-Hancock, HEARD, and Phillimon Simwaba, DHAT) and VSO (Jessica Reuter) the idea emerged of introducing a disability networking zone (DNZ) at the Vienna international AIDS conference under the leadership of the IDDC.

Other key populations, such as sex workers, men having sex with men, injecting drug users and mobile populations were often the subject of research and development activity given their generally-recognised vulnerability to and risk of HIV infection. Although people with disabilities share similar risky behaviours, such as a lack of condom utilisation, multiple partnerships, lack of HIV knowledge and limited safe sex negotiation skills^{33, 34}, their sexual and HIV rights only started to be recognised a few years ago, as explained in the section that follows. The DNZ has made a considerable contribution to this recognition by creating both an international exchange network and an advocacy mechanism with the International AIDS Society itself.

B

Description of the good practice

The first time that disability was seen to emerge from the shadows at international AIDS conferences was during the 17th IAC in Mexico City and 15th ICASA in Dakar, Senegal in 2008, where various organisations and institutes, such as AIDS Free World, Handicap International, the Health Economics and HIV/AIDS Research Division (HEARD) of the Kwa-Zulu-Natal University and national-based DPOs, took part in specific HIV and disability-related events. This increased participation was also due the motion introduced by the Africa Campaign on Disability and HIV and AIDS.

Over the years, one of the main objectives of the IDDC HIV/Disability Task Group, of which Handicap International is an active member and was co-chair from 2010–2012, has been to ensure that disability is included in AIDS conferences' mainstream programming. This inclusion draws attention to the need for the unaddressed reality of people with disabilities in relation to the HIV epidemic to be addressed at a global level and for their accessibility rights to be integrated into new research, programme decisions and initiatives. The following conference activities were undertaken by one or a consortium of organisations to push for more disability inclusive agendas: special and satellite sessions (ICASA 2008 and IAC 2010), forum (IAC 2008 and 2012³⁵), non-abstract driven sessions (ICASA 2011 and 2013³⁶), skills building workshop (IAC 2012 and 2014), symposium (ICASA 2013³⁷), disability networking zone (IAC 2010, ICASA 2011, IAC 2012, ICASA 2013, IAC 2014), and promotion of disabled speakers in plenary sessions (ICASA 2013).

Hence, from one AIDS conference to another, the members of the consortium gained experience and learned lessons on how to

develop better group strategy by capitalising on their complementary strengths and cumulative organisational networks throughout the world. To illustrate the

building blocks of disability inclusion in AIDS conferences over the years, the Table below summarises the successive successes.

AIDS conference	Member of the International Steering Committee	Disability specialists and experts in scientific committee	Disability accessibility audit	Disability and HIV abstracts selected	Special session or satellite session or forum on HIV and disability	Non-abstract driven session on HIV and disability	Skills building workshops or symposium on HIV and disability	Disability networking zone	Active involvement of local DPOs and partners in organising activities	Persons with disabilities living with HIV in plenary sessions	Disability and HIV officially in the rapporteurs' session
IAC 2008	No ^A	No	No	Yes	Yes	No	No	Yes ^B	No	No	No
ICASA 2008	No	No	No	Yes	Yes	No	No	No	Yes ^C	No	No
IAC 2010	No	No	Yes	Yes	Yes	No	No	Yes ^D	No	No	No
ICASA 2011	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes	No	Yes
IAC 2012	No	No	Yes	Yes	No	No	Yes	Yes	Yes	No	Yes
ICASA 2013	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes
IAC 2014	No	No	Yes	Yes	No	Yes	Yes	Yes	Yes	No ^E	No

A: But AIDS Free World was

B: A small one

C: Through the Africa Campaign

D: First group effort

E: But disability mentioned by speakers

Initiative 6

As can be seen in the above table, the success of disability inclusion in conferences has been the result of years of advocacy and collaborative work; the above results were not achieved overnight. They are due to tireless joint work undertaken by specific organisations, such as IDDC members, which decided to join forces to carry out disability-based advocacy from the inception to the finalisation stage of each AIDS conference. In the earlier AIDS conferences (e.g. from 2008 to 2010), disability had begun to be included, but its visibility was limited to a special event and a forum on HIV and disability. However from 2010 onwards, other key activities were added, such as non-abstract driven sessions (two) on HIV and disability at the 2011 ICASA and skills building workshops (two) on HIV and disability at the 2012 IAC. At both the sessions and the workshops, UNAIDS top representatives (deputy executive directors) spoke of the importance of the intersection between HIV and disability. This key breakthrough resulted from constant collaborative lobbying for disability inclusion, and was helped by the fact that UNAIDS had gradually started to take action since the drafting of the 2009 Disability and HIV/AIDS Policy Brief³⁸.

Handicap International received an honorary medal from the Ethiopian Government following the 2011 ICASA in Addis Ababa for its work (and that of its partners) as an official member of the International Steering Committee on ensuring a strong message was delivered on the need to include people with disabilities and disability issues during the conference and beyond³⁹.

Moreover, the disability-led organisations, DPOs and research institutes which were part of the IDDC alliance became more organised and proactive with regular international Skype calls and tasks assigned among themselves to better identify facilitating factors and solve political bottlenecks related to AIDS conferences as they emerge. Having direct access to key organisers as part of the International Steering Committee

(during ICASA 2011 and 2013) enabled many IDDC-affiliated organisations to take part in decision-making processes and obtain essential information for use in debates by all the members of the Consortium.

C

Most significant changes

- **Importance of maintaining the momentum among members:** One significant change is that the IAC and ICASA AIDS conferences have become more accessible for people with disabilities. Before negotiations with the DNZ network (composed of IDDC members and local DPO partners based in each AIDS conference organising country) started, international AIDS conferences were not accessible to people with disabilities. Over the years, thanks to feedback meetings which became regular from 2010 onward after the DNZ closed at the IAC conference, the DNZ network advocated successfully for: a) accessibility of the website for the blind, b) sign interpreters in the main plenary sessions, c) disability audit before the conference starts, d) conference programme/activities on USB sticks for the blind, e) free entrance to the conference for personal assistants of a person with disabilities, and f) inclusion of disability abstracts in the main programme.
- **People with disabilities living with HIV at the heart of plenary sessions:** From 2008 to 2014, one of the most significant breakthroughs was the selection by the 2013 ICASA organisers of two people with disabilities living with HIV (a deaf gay man and a young disabled mother of two) as keynote speakers in plenary sessions; this had not happened in the annals of AIDS conferences until December 2013. HEARD identified these two South African disabled activists and they were

further supported by the IDDC network via various advocacy initiatives. The usual practice for plenary sessions was to invite imminent researchers (e.g. Prof. Salim Abdool Karim from South Africa), state leaders (e.g. Bill Clinton and George W. Bush Junior), international stars (e.g. Annie Lennox), influential donors (e.g. Dr. Mark Dybul of the Global Fund to Fight against AIDS, Tuberculosis and Malaria) and representatives of communities of sex workers, men having sex with men and young people as keynote speakers—none of whom are disabled and who most are not living openly with HIV either. For many, speaking at a plenary sessions provides the perfect platform for influencing thoughts and practice in the field of HIV and AIDS, as thousands of conference delegates are present to hear about what is most innovative in the field, what are the highest- priority issues in HIV and AIDS, and what strategic directions should be taken in the future. It was possible to have two people with disabilities living with HIV speak at the plenary session because IDDC members know their disabled constituency well and more importantly they know who from the disabled community is ready to disclose her/his HIV status to the world. With this information to hand, the Consortium members kept pushing the 2013 ICASA conference organisers and explaining the importance of including people with disabilities living with HIV among the keynote speakers. Earlier attempts had been made, but this was the first time they proved successful.

- Inclusion of disability in the rapporteur sessions:** Another significant change was the acknowledgement of the intersection of HIV and disability in rapporteur sessions (ICASA 2011 and 2013 and IAC 2012), which was the direct result of the DNZ network’s activities and associated sessions. This proved to be pivotal as disability was no longer invisible in the key take-home messages for conference delegates. Making sure that disability is included in the conclusion notes of any AIDS conferences is crucial for the

next AIDS conference as the conclusion notes influence organisers in choosing what issues to tackle, who to invite, what subjects to include and so on.

D

Impact statements

- From Volderine Hackett, Leadership and Accountability Programme Rapporteur at the International AIDS Conference in Washington, 2012:** “We learned also from the skills building workshop on the inclusion of disability in national strategic plans that despite the ratification of the Convention on the Rights of Persons with Disabilities many countries have not addressed the issues of this group which accounts for 15% of the world’s population... We were told to tell you that universal access, zero infections, zero AIDS-related death and zero discrimination cannot be achieved without including the world largest minority: the disabled.”
- Dr Jill Hanass-Hancock, Senior Researcher and Specialist (HEARD):** “HEARD has enjoyed the journey with the DNZ right from the start. It has enabled us to network with many different players around the globe, but in particular to develop a strong network to push the agenda of disability and HIV in Eastern and Southern Africa forward. It has also enabled us to utilise our research and make it available to a large audience... Over the years, we have ensured that everybody can contribute equally to the DNZ programme and that the DNZ is not dominated by the agenda of a few organisations. We have united researchers, advocates and people with disabilities; (this) is one of the biggest achievements of the DNZ. It has also seen some of the most cutting-edge disability research presentations, some of the most innovative interventions and multimedia

pieces and mastered the engagement with key stakeholders in round table discussions at the zone. The DNZ is one of the few places that I have experienced in which one can truly find equality and innovation. It is really driven by the slogan “Nothing about us without all of us!”

- **Phillimon Simwaba, Executive Director of DHAT:** “Through the DNZ, DHAT has benefited from this kind of Networking Zone in many ways. We benefited from knowledge-sharing of good practice, research findings and presented many presentations on Disability and HIV. The DNZ has also enabled a lot of people with disabilities living with HIV to share their experiences. DHAT truly considers the DNZ as a place of networking where people with disabilities can tell their stories openly and without stigma. It is a place that allows people with disabilities to be part of society and can create an inclusive society through emerging issues evolving around HIV, sexual and reproductive health rights, tuberculosis and disability.”

goal of advancing the inclusion of disability in international AIDS conferences.

Existing organisational, technical and financial resources were optimised according to the existing capacities of each partner organisation to plan and organise international-based activities and respond to emerging conference organisation-related issues through consultative consensus, advocacy-based letters/documents and evidence-based arguments.

- **Keeping the memory of key events alive via key IDDC HIV/Disability Task Group members over the years:** Since the Africa Campaign on Disability and HIV and AIDS, a number of members have kept the momentum alive despite certain upheavals (such as changes in human resources) and diminishing financial resources. For instance, VSO, EU-CORD, Handicap International, DPOD, SightSavers, HEARD, DHAT and the University of Johannesburg have each cochaired the Task Group to keep actions going with clear deliverables. Documenting the Group’s good practices, lessons learned and activities online and making all this available to all has helped reflect back on and keep track of what issues remain to be accomplished during future conferences.
- **Official membership of the International Steering Committee:** For ICASA 2011, one of the members of the Consortium (Handicap International) was officially selected as a member of the ICASA International Steering Committee. This membership was an “eye and ear” opener. As an ICASA decision-maker and organiser, suddenly key meetings, decisions, lists of topics and speakers were available for discussion, debate and decision. But even from the inside it was not always easy to promote the rights of people with disabilities in a field that has often failed to recognise their risks to HIV. This may have been due to economics and the allocation of limited resources to a growing group of people needing HIV prevention, care and treatment services; nonetheless, teams worked diligently to prevent any removal



E

Facilitating factors that made this practice successful

In hindsight many of the facilitating factors were learned from one conference to another. Having key members who had attended earlier AIDS conferences also greatly helped with not reinventing the wheel. More specifically, the facilitating factors are as follows:

Internal facilitating factors via the IDDC HIV/Disability Task Group:

- **Representing the voice of many through the IDDC and moving forward as a multi-stakeholder alliance:** Over the years, the members of the IDDC HIV/Disability Task Group learned to work better as a team to achieve their shared

of what had been decided or accepted in terms of disability visibility and/or disability-inclusive sessions and activities.

➤ **Harnessing the passion of activists and advocates:**

Another key factor was that many of the most active members and co-chairs of the Consortium already had operational programmes or sector-based activities on HIV and disability as part of their organisational priorities. This facilitated not only their organisational engagement but also increased their individual commitment to the cause of disability inclusion in HIV policy and programming. It was the essence and driver for each member to bring inclusion to another level and to capitalise on each other's successes.

➤ **Having an office or members or their partners in the city where meetings and the AIDS conference were taking place:**

From 2010 onwards, members of the Consortium understood the importance of having a physical presence in the country where the AIDS conference would be organised. Whether for attending meetings, ensuring constant follow-up in person, undertaking a disability accessibility audit with the support of people with disabilities and DPOs, or getting material in and out of the conference venue, being geographically present was imperative to be more effective and efficient. Furthermore, having a member on site was useful for other members coming from abroad, reducing hassle and logistical problems.

➤ **Involving local DPOs and their members with experience on the intersection between HIV and disability:**

Involving local DPOs in organising Disability Networking Zones (DNZ) at AIDS conferences started at the ICASA 2011 when various Ethiopian DPOs played a significant part in jointly setting up the DNZ, providing volunteers, assisting with sign language interpreters and supporting disability accessibility audits. At the IAC 2012 in Washington, leading American DPOs helped increase disability visibility. In ICASA 2013, South African DPOs took

on many of the logistical responsibilities, undertook disability accessibility audits and even persuaded UNAIDS' Eastern and Southern Regional Support Team to provide financial support for the organisation of the DNZ. In Melbourne IAC 2014, the Australian disability organisations and sector proved to be one of the most effective partners in organising, implementing and monitoring DNZ activities, also obtaining visibility in the press. The transfer of skills from members of the IDDC Consortium to the local level represents a major achievement.

➤ **Getting UNAIDS on board:** UNAIDS is the international leader on HIV and AIDS policies and guidelines and the main advocate for comprehensive and coordinated global action on the HIV epidemic. In 2009 and 2012, UNAIDS officially acknowledged the importance of addressing the vulnerability of people with disabilities in its Policy Brief on Disability and HIV and Strategy for Integrating Disability into AIDS Programmes (under review) respectively. Having UNAIDS top decision-makers as speakers on the intersection between HIV and disability was instrumental in gaining more programme credibility at the global level. UNAIDS also supported key activities such as sponsoring disabled speakers for ICASA in 2011 and the printing of key dissemination documents on HIV and disability.

➤ **Involving Research Organisations:**

The DNZ was supported in its infancy by researchers who brought the issue to the attention of the IDDC. Over the years the DNZ has ensured that it keeps close links with research organisations and is informed by the most up-to-date data available on the intersection of HIV. In this way the DNZ has ensured that the vulnerability of people with disabilities, as well as the disabling effects of HIV as shown in research have been highlighted in the DNZ, uniting two distinct issues that need similar and complementary solutions.

External factors at international level:

- **Ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2006):** So far more than 145 countries⁴⁰ worldwide have ratified the Convention. Binding in its nature, the Convention calls upon governments to put in place concrete accessible measures for people with disabilities at all levels. For instance, Article 31 (on statistics and data collection) and Article 32 (on international cooperation) stipulate that “State Parties undertake to collect appropriate information, including statistics and research data...” and ensure that “international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities”.
- **International high-level events and publications:** In June 2011, WHO and the World Bank published the first World Report on Disability⁴¹ estimating that 15% of the world’s population lives with a disability, and 2–3% lives with severe disabilities. Two years later, a High-Level Meeting on Disability and Development was organised in September 2013⁴² to discuss the importance of disability inclusion in post-MDG dialogues. These two high level events were used by 2013 ICASA organisers to argue that an international AIDS conference that devotes much of its programme to rights promotion and advocacy for universal access to all could not possibly continue ignoring one billion people worldwide in its global response.
- In 2011, the IDDC task group on disability and HIV was part of the development of the **Disability-inclusive Framework for National Strategic Plans for HIV**⁴³. This framework can now be used to inform governments on how to move forward with the inclusion of disability in HIV programming.

F

Barriers or challenges

- **No specific funding for disability-inclusive AIDS conference-related activities:** One of the biggest challenges for members in participating in AIDS conferences and organisation activities (such as printing of communication material, refreshment for volunteers, hiring of sign language interpreters, and printing material in Braille) was the lack of specific funding to run these activities. These activities were funded through the pooling of existing organisational resources from members that could afford to support the joint Consortium initiative. So far the group has been able to cope thanks to creative ideas and solidarity. Nonetheless, obtaining specific financial resources would reduce stress and allow better use of time for dealing with other programme issues. Furthermore, the Consortium has rarely been able to sponsor participants other than their own implementing partners when project funding allowed for it to happen.
- **Lack of knowledge among AIDS conference organisers on accessible HIV policies and programming for people with disabilities:** A lack of knowledge and skills on disability inclusion among AIDS conference organisers can be detrimental to the HIV-related rights of people with disabilities. Ignorance of HIV risks among people with disabilities coupled with limited knowledge among AIDS conference organisers and scientists can lead to negative attitudes towards people with disabilities and a lack of priority for disability in research and development. As a result, a vicious cycle of invisibility creates further “unconscious” neglect of one of the largest minorities of the world. Fortunately with determination, continuous awareness-creation, capacity-

building and evidence-based advocacy, this situation has been gradually improving. Yet this is only the beginning of the changes needed in a global environment intricately linked to international policies, domestic laws, national responsibility and public awareness.

- **Lack of enforcement of International Convention, policies and laws on disability rights:** Though most of the African countries where the burden of HIV is highest and most AIDS-related donors have ratified the UNCRPD, very few have respected their commitment to the billions of people with disabilities. This remains not only an ethical issue internationally, but also hampers the universal coverage of HIV prevention, treatment, care and support services for all, and thus, facilitates the continuation of the propagation of HIV epidemic among very underserved populations such as the disabled.

G

Analysis

This good practice on inclusive AIDS conferences is a perfect example of how an organised and unified multi-stakeholder group with members from different contexts and countries sharing the same vision and growing stronger over time leads to the more effective outcomes over time. In this case, having a complementary vision was seen as an asset, rather than a reason to compete in order to achieve common objectives. Coupled with this, having access to the top conference organisers and decision-makers enabled disability activists and development workers to understand where they were coming from and tailor evidence-based strategies to convince them of disability inclusion. Hence inclusion of disability was facilitated by knowing who to approach and which doors to knock on. This was made possible

by being part of the International Steering Committee. In instances where members were not part of any official committees (e.g. during the 2012 IAC), it would have been useful to know and approach other networks without losing sight of the ultimate agenda for inclusiveness and accessibility. As the proverb says, “out of sight, out of mind”, so it is of the utmost importance to be part of decision-making processes in order to voice the rights of people with disabilities on appropriate platforms—either directly or through the voice of a partner briefed prior to key meetings. The different strategies employed and the various enabling factors put in place can be replicated at other conferences where disability mainstreaming is lacking. For instance at the end of ICASA in 2011, all disabled and non-disabled delegates of the Consortium decided to organise a silent protest outside the main conference doors through which all the delegates had to pass; this was intended as an illustration of the barriers faced by people with disabilities to access HIV information and services.

The demonstrable impact of these efforts can be seen in the change of attitudes of AIDS conference organisers over time, the number of disability-related initiatives organised, and the quality and depth of discussions and papers on the intersection between HIV and disability and the implication of disabled people living with HIV and their representatives.

H

Recommendations for HIV and AIDS practitioners

The key recommendations related to this good practice are as follows:

- Whenever possible, be a member of the International Steering Committee for international AIDS conferences, or use the wisdom of the network to lobby and

advocate if the first option is not available. Membership is crucial for obtaining privileged access to key conference organisers and decision-makers.

- Propose and implement convincing changes for accessibility and disability inclusion as a group representing a large constituency and composed of a multi-stakeholder group (DPOs, NGOs, research institutes, activists and academicians). As such, advocacy work should always be accompanied by awareness-raising so as to promote knowledge acquisition and attitude change among conference organisers.
- Always use evidence-based advocacy coupled with testimonies about the reality of the risks and vulnerability of women, men and youth with disabilities in the face of the HIV epidemic.
- Monitor the extent to which new developments to come out of international conferences are being incorporated into domestic laws and policies and whether there is congruency and synergy with international AIDS policies and programming (from UNAIDS, but also from main HIV related donors).
- Study the conference mechanism well— who is doing what, when are the key meetings being held before the conference and where; when are pre and final decisions taken; when are deadlines, etc.— so that a tactical approach can be adopted among members and partners who want to organise disability inclusive sessions, and promote disabled keynote speakers in plenary sessions and dynamic disability networking zones.
- Insist on accessible rooms, infrastructures (e.g. toilets and platforms) and conference services, such as sign language interpretation, a disability desk, large print materials out of respect for the right of people with disabilities to participate and get involved.
- Act as a group and focus on one international conference (with 5,000–10,000 delegates and more) at a time, to optimise joint efforts, time and

limited resources and achieve greater impact.

- As early as possible (at least 6 months before the conference) seek financial opportunities for funding part or all activities, especially the sponsoring of partners and people with disabilities and their assistants if needed.



Kenya, 2005

Conclusion

On the eve of the redefinition of the post-2015 development agenda, disability inclusion through accessibility and universal access has gained in importance, reflecting the urgent need to fully include the world's biggest minority: people with disabilities constitute 15% of the population worldwide and this rate is closer to 19% among the world's female population. There is growing evidence that people with disabilities, women in particular, are not only at risk and vulnerable to HIV infection, but are more likely to be infected by HIV than non-disabled people in Sub-Saharan Africa. Therefore, a special focus on what works in the field of HIV and disability is opportune, especially with the recent release of UNAIDS' Gap Report which devoted a whole chapter to HIV and AIDS among people with disabilities.

The key lessons learned from these good practices across diverse countries and contexts are as follows:

- Investing in and collecting epidemiological and behavioural data among people with disabilities are powerful technical and advocacy tools for policy improvement and change towards more inclusiveness of all. Visible data on disability can convince policy-makers and programme managers to change course and stop excluding people with disabilities from the HIV response.
 - The importance of buy-in by top managers and decision-makers should not be underestimated, as they play a crucial role in improving programmatic access for people with disabilities to HIV prevention, treatment, care and support services through resources commitment and political engagement.
 - Building the capacity of all HIV prevention and response service providers is essential to ensure the provision of accessible disability- and gender-sensitive information and services.
 - Universal design and/or reasonable accommodation are key aspects of disability mainstreaming at all levels of HIV-related development for people with disabilities.
- The institutional development of disabled people's organisations is pivotal for strengthening the promotion and defence of disability rights in the global HIV response.
 - Directly involving women, men and children with disabilities and representatives of disabled people's organisations in the design, implementation, monitoring and evaluation of HIV prevention and response services increases the quality of interventions and the relevance of actions.
 - Partnerships between AIDS-related research and academic institutions and disability-focused NGOs/disabled people's organisations is necessary to build meaningful alliances for disability inclusion in HIV and AIDS programming.

General solutions to HIV and AIDS are no longer sufficient, given the heterogeneity of the world's population. It is now essential to know what works for the key and vulnerable groups that are often left behind, such as people with disabilities who encounter specific structural, attitudinal and environmental barriers. This process of documenting good practices on disability inclusion in HIV and AIDS policy and programming has shown that adopting a twin-track approach to inclusion is a fundamental requirement. These good practices also demonstrate that core principles of rights and access to services for people with disabilities cannot be minimized, even in hectic development environments and amid seemingly competing programmatic priorities.

Handicap International has already begun to integrate these lessons learned into new practices, such as in Senegal as part of a new project (2013–2016) funded by the 5% Initiative and aims at improving the Global Fund's mechanism, and in Mali (2014–2016) where a special focus will be put on disability inclusion via the governance processes of community-based AIDS organisations. Handicap International encourages other international development, government and

List of abbreviations

health actors to review, use and especially to act upon these good practices in future disability-inclusive policy and programming initiatives.

AFD	Agence française de développement (International Development Agency of France)
AIDS	Acquired Immune Deficiency Syndrome
BCC	Behaviour Change and Communication
IDDC	International Disability and Development Consortium
IEC	Information, Education and Communication
HIV	Human Immunodeficiency Virus
DPO	Disabled People's Organisation
KAP	Knowledge, Attitudes and Practices
NAC	National AIDS Council
NSP	National AIDS Strategic Plan
PEPFAR	President's Emergency Plan for AIDS Relief
SGBV	Sexual and Gender-Based Violence
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing

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Footnotes

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the 1990s, the number of people in the UK who are aged 65 and over has increased from 10.5 million to 13.5 million (1990-2000) (Office for National Statistics 2001).

There is a growing awareness of the need to address the needs of older people in the UK. The Department of Health (2000) has published a strategy for older people, which sets out a vision for the future of health care for older people. The strategy is based on the following principles:

• To ensure that older people have access to the services they need to live well and to die with dignity.

• To ensure that older people are treated as individuals and that their views are taken into account in decisions about their care.

• To ensure that older people are able to live independently and to participate in the community.

• To ensure that older people are able to live in their own homes and to receive care in their own homes where possible.

• To ensure that older people are able to live in a safe and secure environment.

• To ensure that older people are able to live in a community that is supportive and caring.

• To ensure that older people are able to live in a community that is accessible and inclusive.

• To ensure that older people are able to live in a community that is healthy and vibrant.

• To ensure that older people are able to live in a community that is safe and secure.

• To ensure that older people are able to live in a community that is supportive and caring.

• To ensure that older people are able to live in a community that is accessible and inclusive.

• To ensure that older people are able to live in a community that is healthy and vibrant.

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• To ensure that older people are able to live in a community that is healthy and vibrant.

• To ensure that older people are able to live in a community that is safe and secure.



Including disability in HIV policy and programming: Good practices drawn from country-based evidence

The purpose of this document is to share good practices and processes concerning the inclusion of disability issues in HIV policy and programming, drawing on specific experiences in Senegal, Ethiopia, Kenya, Rwanda and Cambodia and on lessons learned at international AIDS conferences. More specifically, it is intended to 1) provide a clear indication to HIV and AIDS practitioners that disability mainstreaming in HIV and AIDS is indeed possible and workable in various contexts and by implementing specific steps/initiatives; 2) transfer concrete knowledge and practices to disability stakeholders, including disabled people's organisations, on how to work in HIV and AIDS; and 3) persuade HIV-related development partners that more investment is needed to develop this knowledge base in order to bring about practical changes at micro, meso and macro levels, as well as among the population.

The good practices are also intended to inspire and motivate other organisations and agencies to use and replicate them in other contexts and countries, if/when they are adapted to the needs and situations of people with disabilities and communities.

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