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A NOTE ON LANGUAGE

In all our disability work, VSO seeks to be guided by disabled people. This includes the language we use. In general, this handbook refers to 'disabled people', because this is the phrase used by Disabled People's International, the worldwide network of disabled people's movements.

In many countries where we work, the national disability movement uses different language – for example, 'people with disabilities' is very common in English speaking countries. DREAM-IT partners in Indonesia use 'diffable', to highlight that disability is not the same as not being able. As far as possible, case studies use the language preferred in that country. This handbook is not intended to create a standard terminology for VSO. In each country, VSO should use the same language as the national disability movement.



This publication has been produced with the assistance of the European Union. The contents of this publication are the sole responsibility of VSO and can in no way be taken to reflect the views of the European Commission.

VSO'S STATEMENT OF VALUES

VSO believes that everyone must be able to exercise their fundamental human rights.

VSO aims to support disabled people in exercising their rights, and to promote their full inclusion and active participation as equal members of their families, communities and societies.

Focus for Change, VSO's Strategic Plan 2002

VSO is committed to tackling disadvantage and exclusion by empowering disadvantaged people to claim and exercise their rights.

For VSO staff and volunteers working in disability, this means promoting the full inclusion and active participation of disabled people within their families, communities and societies. To pursue this aim, we always work in partnership with disabled people's organisations, as well as a range of other organisations depending on the context of each programme.

All VSO staff and volunteers are expected to pursue their work in line with VSO's beliefs and values.

This means:

- **not discriminating ourselves against anyone on the basis of disability or any other factor**
- **promoting equity, non-discrimination and the inclusion and participation of disadvantaged people, including disabled people, in our own work and that of VSO's partners**

A HANDBOOK ON MAINSTREAMING DISABILITY

VSO'S STATEMENT OF VALUES	1
ABBREVIATIONS	4
INTRODUCTION	5
CHAPTER 1: OVERVIEW	6
Key messages	6
What is disability?	6
What is mainstreaming?	8
The mainstreaming model	8
Why mainstream disability?	9
Disability programmes	9
Non-disability programmes	10
Key resources	13
CHAPTER 2: DISCRIMINATION, STIGMA AND INTERACTING WITH DISABLED PEOPLE	14
Key messages	14
Discrimination	14
Fear	14
Invisibility and ignorance	15
Stigma	15
Disability and other forms of discrimination	17
Challenging discrimination	18
Interacting with disabled people	19
Interacting with people with mobility impairments	19
Interacting with people with hearing impairments	20
Interacting with people with visual impairments	20
Interacting with people with learning difficulties	21
Language	22
Case studies	23
1. VSO Indonesia: enabling a disabled man to participate in his community	23
2. VSO Papua New Guinea: disabled people challenging discrimination	23
CHAPTER 3: ORGANISATIONAL COMMITMENT	26
Key messages	26
Practical advice and lessons	26
Case studies	29
3. VSO Thailand: developing a focus on inclusion	29
Key resources	33
CHAPTER 4: SENSITISATION	34
Key messages	34
Practical advice and lessons	34
General	34
Informal interaction with disabled people	35
Disability equality training	36
Practical skills training	39
Follow ups	39
Case study	40
4. VSO Indonesia: sensitisation	40
Key resources	43

CHAPTER 5: WORKPLACE MAINSTREAMING	44
Key messages	44
Practical advice and lessons	44
Recruiting disabled people	44
Office environment	46
Staff	46
Policies and processes	47
Accessible communication and documents	49
Review and follow-up	50
Case studies	50
5. VSO Indonesia: office adaptation and secondments	50
6. VSO India: staff sensitisation, office adaptation and recruitment	52
7. VSO UK: disabled volunteers	55
8. VSO The Philippines: working with Deaf volunteers and Deaf partners	58
Key resources	59
CHAPTER 6: PROGRAMME MAINSTREAMING: INCLUDING DISABLED PEOPLE IN PROGRAMME MANAGEMENT PROCESSES	60
Key messages	60
Practical advice and lessons	60
Who to involve and how	60
Where to involve them	62
Making meetings and workshops accessible	66
Case studies	69
9. DREAM-IT evaluation exchange	69
10. VSO Namibia: Project Steering Committee and Project Management Team	71
11. VSO The Gambia: strategic planning and programme development	72
Key resources	74
CHAPTER 7: PROGRAMME MAINSTREAMING: INCLUDING DISABLED PEOPLE IN OTHER PROGRAMME AREAS AND SECTORS	76
Section 1: General	76
Key messages	76
Practical advice and lessons	76
Planning	78
Persuading	78
Doing	79
Reviewing and follow-up	80
Section 2: Programme mainstreaming: education programmes	81
Key messages	82
Practical advice and lessons	82
Planning	83
Persuading	83
Doing	85
Reviewing and follow-up	86
Case study	87
12. VSO Namibia: inclusive education	87
Key resources	88
Section 3: Programme mainstreaming: HIV and AIDS programmes	89
Key messages	89
Practical advice and lessons	89
Planning	89
Persuading	90
Doing	90
Reviewing and follow-up	91
Case Studies	91
13. VSO Ghana: Protect Yourself	91
14. VSO Namibia: HIV & AIDS and disability	92
Key resources:	95
Section 4: Programme mainstreaming: other goals	96
Key messages	97

Practical advice and lessons	97
Planning	97
Persuading	97
Doing	98
Reviewing and follow-up	98
Case studies	98
15. VSO Indonesia: Programme Area Plan Development	98
16. Pakistan and Sri Lanka: emergency relief	100
Key resources	100
<hr/>	
CHAPTER 8: POLICY	102
Key messages	102
Practical advice and lessons	102
VSO as facilitator	102
Effective advocacy	104
Allies	106
Media	107
Research	107
Case studies	109
17. VSO DREAM-IT: Fifth Asia-Europe People's Forum (ASEM-PF 5)	109
18. VSO Ghana: PRSP consultation	111
19. VSO Kenya: PRSP consultation and Constitutional review	112
Key resources	112

ABBREVIATIONS

ASO	AIDS service organisation
CBR	community-based rehabilitation
CRC	UN Convention on the Rights of the Child
DPO	disabled people's organisation
DREAM-IT	Disability Rights, Empowerment, Awareness & Mobilisation – Indonesia & Thailand
EARC	Education Assessment & Resource Centre
HBC	home-based care
INGO	international non-governmental organisation
IPG	VSO International Programmes Group
MDG	Millennium Development Goal
NGO	non-governmental organisation
PAP	Programme Area Plan
PRSP	Poverty Reduction Strategy Paper
RPM	Regional Programme Manager
VSO-RAISA	VSO's Regional AIDS Initiative of Southern Africa

INTRODUCTION

This handbook aims to give practical guidance to support development organisations to mainstream disability into their work. It is primarily intended for VSO programmes, but could be useful to other development actors interested in mainstreaming disability, such as NGOs, government and donors.

The handbook is drawn from the experience of VSO DREAM-IT (Disability Rights, Empowerment, Awareness & Mobilisation – Indonesia & Thailand), a five-year disability programme carried out jointly by VSO Indonesia and VSO Thailand. Mainstreaming has been a key theme of this programme from the beginning.

A team from DREAM-IT and VSO International reviewed the lessons from DREAM-IT for this handbook. We interviewed VSO programme staff, volunteers and partner organisations, including disabled people's organisations (DPOs) from around the world, to gather their experiences of mainstreaming. We also consulted disabled people and activists to ensure that the handbook is informed by the perspectives and experiences of disabled people – a principle at the heart of VSO's approach to mainstreaming.

HOW TO USE THIS HANDBOOK

Each chapter of the handbook addresses a key topic in mainstreaming disability.

Chapter 1 gives an overview of disability and mainstreaming, and explains why VSO believes it is important to mainstream disability. It outlines a process for getting started and managing disability mainstreaming. **We recommend that you read this chapter first.**

Chapter 2 explains how discrimination works and how to challenge it on an individual basis. It also includes practical hints and tips on interacting with disabled people, and on appropriate language. **You will probably find it useful to read this chapter whatever topics you are interested in.**

Chapters 3 to 8 cover the different elements of VSO's mainstreaming model:

- **Chapter 3** Organisational commitment
- **Chapter 4** Sensitisation
- **Chapter 5** Workplace mainstreaming
- **Chapter 6** Programme mainstreaming: including disabled people in programme management processes
- **Chapter 7** Programme mainstreaming: including disabled people in other programme areas and sectors
 - Section 1 General
 - Section 2 Mainstreaming disability into education programmes
 - Section 3 Mainstreaming disability into HIV & AIDS programmes
 - Section 4 Mainstreaming disability into other programme areas and sectors
- **Chapter 8** Policy

Each chapter or section follows the same basic structure:

- An introduction to the topic, followed by key messages
- Practical advice and lessons, illustrated by real examples
- Case studies from VSO DREAM-IT and VSO's wider mainstreaming experience
- Key resources available on the internet

If you are interested in a specific topic, it should be possible to read the relevant chapter on its own. Over time, as you develop your mainstreaming work, we hope you will work through the entire handbook.

CHAPTER 1: OVERVIEW

KEY MESSAGES

- Disability, and disability mainstreaming, are essentially matters of rights.
- It is essential that disabled people and their organisations play an active role in all mainstreaming activities.
- Mainstreaming is about building disability into existing agendas, frameworks and processes, **not adding on separate disability activities**.
- Effective mainstreaming requires strong management commitment. It needs a clear structure, with ongoing activities and follow-up, and appropriate budget and time allocated to it. It cannot be a 'one-off' activity, or left to individuals with no wider support.
- Remember that disabled people are not a single group – they have different priorities and face different levels of discrimination. In particular, disabled women and girls may face double discrimination based on both disability and gender.
- It is necessary to address both people's specific needs as a result of their impairment, and also the wider social issues of discrimination and exclusion.

WHAT IS DISABILITY?

VSO understands disability as:

The disadvantage and exclusion which arise as an outcome of the interactions between people who have impairments and the social and environmental barriers they face due to the failure of society to take account of their rights and needs

There is a very important distinction in this definition between **impairment** and **disability**.

An impairment is:

A physical, intellectual, mental or sensory characteristic or condition, which places limitations on an individual's personal or social functioning in comparison with someone who does not have that characteristic or condition

In other words, **impairment is individual**. There are as many different impairments as there are impaired individuals. An impairment can be the result of illness, injury, or a congenital condition. For example, different impairments can affect someone's physical mobility or dexterity, her ability to learn, to communicate or interact with other people or to hear or see.

In contrast, **disability is social**. It is the exclusion of people with impairments, due to social and environmental discrimination that acts as a barrier to their full and equal participation in mainstream society. Disability is fundamentally an issue of rights.

In day-to-day speech, the words impairment and disability are often used interchangeably. It's easy to think that they are the same and that disabled people's participation in mainstream society is limited purely because they have an impairment.

However, having an impairment does not necessarily limit or exclude people. For example, in marathons wheelchair users compete separately from runners, because they are so much faster over a long distance on level ground. Yet the same wheelchair user who beat all the runners might not be able to attend a social event after the marathon, if it is held in a building with steps. This is not because she uses a wheelchair but because the building was not built in an accessible way. This is not because of cost – building a ramp would have cost the same amount as building steps – but because the architect and builder did not consider disabled people's access. In other words, the wheelchair user is excluded because her needs are not considered as important as those of other people – she is excluded as a result of (often unconscious) **discrimination**.

Discrimination limits disabled people's most fundamental rights. Where polling cards are not available in Braille or another accessible format, blind people are denied their right to vote. Where schools have no sign language translation, Deaf people are denied their right to education. Where hospitals do not provide information in simple, accessible ways, people with learning difficulties are denied their right to know what is wrong with them or to make decisions about their treatment. Where wells or latrines are physically inaccessible, people with mobility impairments are denied their rights to clean water and sanitation.

VSO understands disability as the **exclusion** of people with impairments from family and social life, equal education, employment and access to basic services because of discrimination. This is also known as the **social model** of disability. VSO uses the social model because it has been developed by disabled people, and best represents their experiences and perspectives.

The social model of disability is often contrasted with the **medical model**, which says that disability is the same as impairment, and so disability can be fixed using medical treatment or therapy alone.

Whilst VSO is committed to supporting appropriate clinical and therapy services for people with impairments, we believe that this is not enough on its own. It is essential to address the specific needs people have as a result of their impairment. For example, a Deaf person needs to learn to sign, and a polio survivor may need crutches. However, a Deaf child who can use sign language still cannot communicate if her parents, teacher and classmates don't learn it too. A woman who has crutches is still unable to get a loan from a microcredit programme if there is a policy that loans will only be made to women in good health. It is also essential to address these discriminatory barriers.

People with certain kinds of impairment (e.g. leprosy, learning difficulties) are also often discriminated against by other disabled people. Disabled people who belong to another excluded group (e.g. a minority ethnic or religious community, women, slum dwellers) may be multiply excluded: by mainstream society, by other members of their community and by other disabled people.

Although mental ill health is not often considered in discussions of disability, people with mental health problems experience severe discrimination on the basis of their condition. In many countries, the law allows them to be detained without charge and treated without their consent, or denies them the right to make a will, vote or make other decisions. It is not for VSO to define who is and who is not disabled. Some mental health groups have allied themselves with the wider disability movement, and some resist this. However, in general, these organisations focus on issues of rights and discrimination, and use a social model of mental health. It is important to be aware of these parallels, which can also apply to people living with HIV & AIDS (see Chapter 7).

It is particularly important to consider gender issues and the different situations of disabled women and disabled men. Disabled women are still expected to fulfil the same roles and responsibilities as other women in their community. For example, if a girl who has difficulty walking cannot fetch water as a result, her family may consider her less useful than her siblings. They may even feel that she cannot get married because she can't perform the duties expected of a wife. She may therefore be seen as a failure as a woman, making her very vulnerable to neglect and abuse.

Where programme and services are not gender-sensitive, disabled women and girls are doubly likely to be excluded. For example, where a community mobilisation meeting is held at a place and time that means people need to walk a long way in the dark, women are generally less likely to attend. A blind woman, who may need more assistance to make the trip and who is even more vulnerable to assault, is even less likely to attend.

We can only overcome disability by addressing the social barriers that discriminate against and exclude people with impairments. It isn't enough for the impaired individual to change – people without impairments must change too.

WHAT IS MAINSTREAMING?

VSO understands mainstreaming as:

The process of engaging in a structured way with an issue as an organisation, at workplace, programme and policy levels, in order to address, and avoid increasing, the negative effects of that issue

In other words, we see mainstreaming as a method for addressing specific issues in areas where they wouldn't normally be addressed. So far, VSO has used mainstreaming to address disability, HIV & AIDS and gender. It would also be possible to mainstream other issues, such as ethnicity or age.

VSO also understands mainstreaming as a way of achieving a specific result. In disability, mainstreaming is a method to promote **inclusion** and to address the barriers that exclude disabled people from full and equal participation in society. Mainstreaming gender is also primarily about inclusion.

Mainstreaming can also be used to achieve other results. For example, HIV & AIDS mainstreaming can be a method for preventing infection or protecting the organisation from the impact of the pandemic, as well as mitigating its effects on people who are infected and affected.

VSO also recognises that mainstreaming means addressing an issue as an organisation. Personal commitment is central to mainstreaming, and every one of us can challenge discrimination and cultural barriers on an individual, face-to-face, basis. However, in order to broaden and sustain these efforts, it is essential for the whole organisation to engage with the issue, from senior management to frontline and administrative staff.

The mainstreaming model

VSO has developed a mainstreaming model to help programme staff put mainstreaming into practice. This has been adapted from our HIV & AIDS mainstreaming model (developed in 2003), based on our experiences of mainstreaming over the last few years. The model has five interconnected elements:

- **Organisational commitment:** the central organisational commitment to mainstreaming the issue, in terms of values (why the organisation is committed) and purpose (what the organisation hopes to achieve). This commitment underpins all mainstreaming activities.
- **Sensitisation:** the process of building people's engagement with the issue and personal commitment to mainstreaming. Sensitisation is about individuals buying in to the organisational commitment.
- **Workplace mainstreaming:** the process of ensuring that organisational policies and practices in the workplace are inclusive, equitable and non-discriminatory, and do not create barriers or reinforce the negative effects of the issue.

In disability mainstreaming, this is about making appropriate adjustments to workplace policies, practice and environment so that disabled people can participate equally in the workplace, as employees or volunteers.

- **Programme mainstreaming:** the process of ensuring that the organisation's programmes and services are inclusive, equitable and non-discriminatory, and do not create barriers or reinforce the negative effects of the issue. As well as looking at programme design and service delivery, this means including excluded people in programme planning, implementation, management and reviewing.

In disability, this involves non-disability service providers and development organisations including disabled people on an equitable basis, in the same settings as non-disabled people.

- **Policy mainstreaming:** the process of addressing wider policy and institutional barriers that exclude people from equal participation or reinforce the negative effects of the issue.

Two essential principles cut across every element of mainstreaming:

- **Meaningful involvement** of people directly affected by the issue is essential for every element.
In disability, this is famously summed up in the rallying cry of the worldwide disability movement 'Nothing About Us Without Us'.
- **Gender** must also be incorporated as part of every element.
Disabled women are doubly discriminated against, as disabled people and as women. It

is essential that our mainstreaming activities take this into account and include women in an equitable and non-discriminatory way.

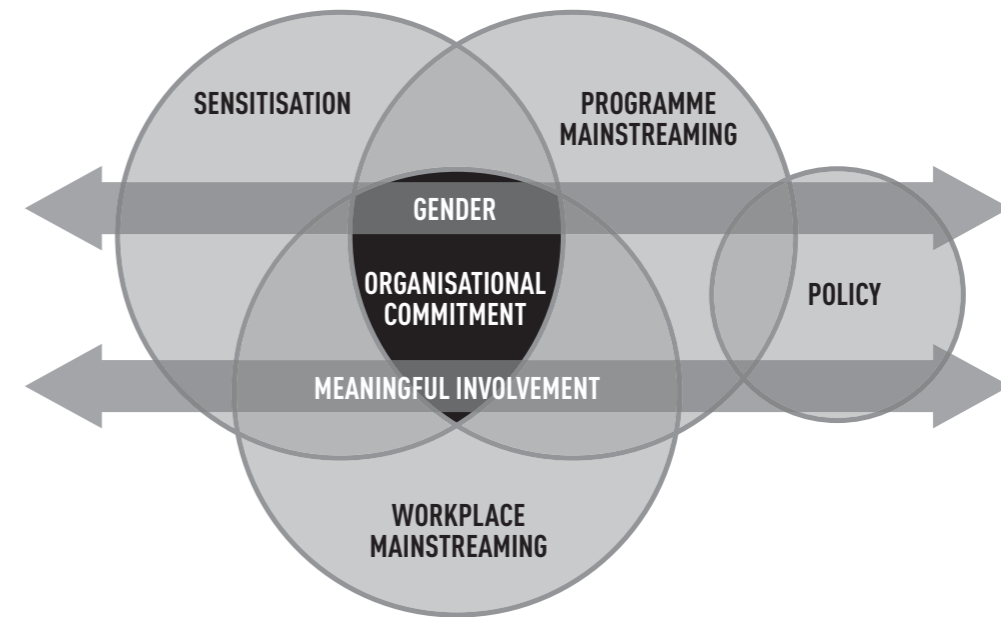


Figure 1: The VSO mainstreaming model

Adapted from HIV & AIDS Mainstreaming Guide for Programme Offices, 2004

Mainstreaming means changing our own internal policies and practices, as well as our programme work. For VSO, because we primarily support partner organisations, mainstreaming also means programme staff and volunteers working with partner organisations to help them make these changes too. In addition to these organisational changes, mainstreaming involves engaging with wider policy barriers.

Whether we work in a VSO programme office, a partner organisation, or another organisation altogether, all the elements of the mainstreaming model are still relevant. Different organisations will begin in different ways, but over time it is essential to address all the elements, and build them into the ongoing work of our organisation.

WHY MAINSTREAM DISABILITY?

'VSO supports a rights-based, inclusive approach which recognises that society must change if disabled people are to achieve full inclusion and active, barrier-free participation.'

Including Disabled People, VSO Position Paper 2001

Disability programmes

The social model of disability shows how disability is the result of discrimination by mainstream society, as people with impairments are excluded (disabled) by structures, policies and practices at every level that discriminate against them, sometimes actively, often by ignoring them. Mainstreaming is essential if we want to tackle the exclusion of disabled people.

Mainstreaming is one of the four key components of VSO's comprehensive response to disability:

- **Voice:** strengthening the voice of disabled people at every level, particularly through building the capacity of disabled people's organisations (DPOs).

- **Inclusive services:** supporting basic services to include disabled people.
- **Enabling services:** strengthening disability services to meet the specific needs of individuals with impairments that prevent them from participating.
- **Mainstreaming.**

Mainstreaming goes hand in hand with strengthening disabled people's own initiatives and organisations as advocates for inclusion and supporting the provision of enabling services (such as mobility assistance, early childhood development or sign language teaching) so that disabled people have the basic assistance they need to participate.

Promoting inclusive services and mainstreaming are basically two different ways of getting mainstream service providers to include disabled people. So far, VSO's support for inclusive services has tended to focus on partner organisations, and has not always led to internal mainstreaming. For example, a number of VSO country programmes currently support ordinary schools to include disabled children (inclusive services), but they have not yet adjusted their own workplace policies and practices or the rest of VSO's programme work in that country (mainstreaming).

Non-disability programmes

Disability mainstreaming is also relevant for programmes that aren't focused specifically on disability. VSO's understanding of development is based on the concept of **disadvantage**. VSO defines disadvantage as people's lack of access to fundamental rights, including education, a livelihood and a voice in decisions that affect them. VSO is committed to tackling disadvantage by working to combat exclusion, powerlessness, income poverty and **denial of rights**.

'VSO believes that everyone must be able to exercise their fundamental human rights.'

Focus for Change, VSO's Strategic Plan 2002

Mainstreaming is essentially a question of **rights**. Everyone, including every disabled person, has the same fundamental human rights, such as the right to life, to information, to freedom of movement, to education, to family life, to decent work and to a voice in decisions that affect them.

However, disabled people are denied these rights in almost every country in the world. We have already seen how disabled people are prevented from exercising their rights in relation to voting, healthcare, water and sanitation where these services are inaccessible to them. They are often denied other basic rights.

The vast majority of disabled people in the South are denied the **right to education**. It is estimated that up to 98% of disabled children in the South are not in school. Even where disabled children do enrol in school, they tend to drop out very soon, because teaching methods are not adapted to their learning needs and because they often suffer abuse from teachers and fellow pupils. This is particularly true for disabled girls. 'Special' education is only available for a tiny minority, and this sort of segregated provision limits disabled children's participation and interaction with their non-disabled peers, besides being prohibitively expensive.

In many countries, people with learning difficulties, mental health problems or complex impairments such as cerebral palsy are often kept confined, either in the family home or in an institution. This might be the result of a deeply-felt desire to protect them, but still denies their fundamental **rights to liberty and freedom of movement**.

Any programme trying to tackle disadvantage or seeking to take a rights-based approach needs to consider the ways in which disabled people are currently excluded and denied their rights. Some programmes working on VSO's Participation & Governance goal, such as VSO Nepal and VSO Pakistan, have already identified disabled people as particularly disadvantaged. These programmes are now building partnerships with DPOs to strengthen their voice in policy and decision-making processes.

'If disability is left out, you will never make poverty history!'

MacDuff Phiri, VSO Ghana, to Jim Wolfensohn April 2005

Disability is still largely invisible in the wider development agenda, in particular the international Millennium Development Goals (MDGs) and country-level Poverty Reduction Strategy Papers (PRSPs). Disabled people are not mentioned explicitly in the MDGs. As a result, most multilateral and bilateral donors, who tend to focus on the MDGs, do not consider disability as a development priority. This is then reflected by national governments and NGOs.

However, there are signs that disability is gaining recognition as a development issue at international level, particularly by the World Bank. The current UN process to develop a Convention on the Rights of Persons with Disabilities offers an enormous opportunity to raise the visibility of disability around the world.

At a national level, if disabled people appear in PRSPs it tends to be under headings like 'safety nets', 'vulnerable groups' or 'special measures', reflecting the assumption that they are not part of the mainstream poverty reduction agenda. This widespread lack of recognition of disability in policy and funding reinforces the exclusion of disabled people.

Yet if disabled people are not included in mainstream development efforts, international and national development targets cannot be achieved. For example, the second Millennium Development Goal (MDG2) is to achieve universal primary education. As we have seen, up to 98% of disabled children in the South are not in school. In any given country, this represents between 5% and 8% of all children – while these children are excluded from education, we can never achieve Education for All.

There are very limited statistics on the prevalence of impairments in the South, reflecting the lack of attention to disability at policy level. Local surveys in different countries suggest that 5% to 8% of any population, or about one person in every two to three households, have an impairment. These surveys do not generally include mental ill health, which the World Health Organisation estimates at 10-12% of the global burden of disease. This is a lot of people to ignore.

In general, the international development agenda is focused on income poverty, rather than rights and inclusion. The relationships between poverty, impairment and disability are complex and poorly understood – not all people with an impairment are poor, and not all poor people have an impairment. Statistics on disability and poverty in the South are almost non-existent, but local studies suggest that disabled people are more likely to be poor than non-disabled people. Disabled people face discriminatory barriers and additional costs to participate in education and employment. As a result, disabled people in the South tend to have lower levels of education, employment and income than the rest of the population. Disabled children are more likely to be neglected and malnourished, and to die young.

So even in terms of poverty reduction, it is essential to include disabled people. For example, MDG4 is to halve the rate of child mortality. Mortality for disabled children under five in the South is estimated at up to 80%, or 4% to 8% of all children under five. While these children are dying in such numbers, it will be extremely difficult to halve child mortality even in the poorest countries in the world.

'... if we are to achieve the Millennium Development Goals of halving poverty by 2015, dealing with education for all, halving the rates of birth and child mortality, it is simply impossible to conceive of doing that without the inclusion of the disabled community.'

Jim Wolfensohn, President of the World Bank November 2004

How to approach mainstreaming

Mainstreaming is an ongoing process of including disability into all our work. However, this process can seem so huge that we never start. Looking at the experiences gathered for this handbook, we found it was most helpful to think about mainstreaming as a project. Like any other project, it is important to plan and budget first, carry out some activities, then review progress and make a new plan to follow up.

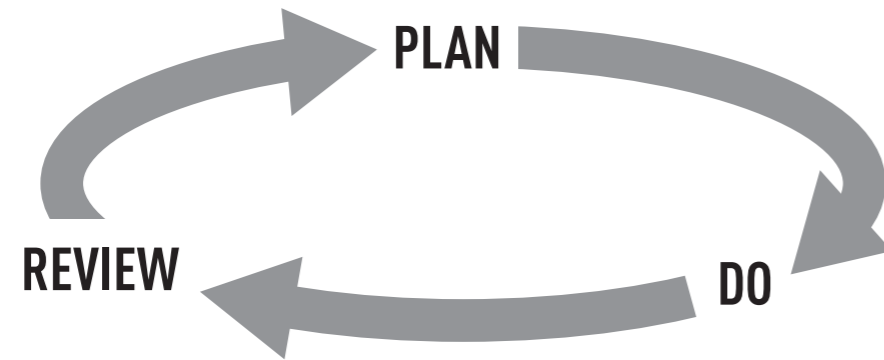


Figure 2: The project cycle

Mainstreaming starts with us. We can all be role models of more equitable and inclusive relationships between disabled and non-disabled people. We can all interact with the disabled people we see around us, and challenge discrimination when we encounter it. However, mainstreaming cannot be left to individuals – we found many examples where committed people had started initiatives, but these had lost momentum. Mainstreaming needs wider organisational support and management commitment.

Mainstreaming usually involves working on an issue that would not ordinarily be seen as the core focus of the organisation, so it is very vulnerable to pressure from other priorities. This is another reason why management support is so important. It also means that mainstreaming projects need a clear long-term structure, with ongoing activities and follow-up, and appropriate budget and time allocated. We found many examples where initial efforts, especially sensitisation activities, were not continued because there were no concrete actions and resources for people to follow up.

It is essential to involve disabled people in the process of mainstreaming from the beginning, and to build relationships with DPOs, who can guide, advise and support us. This ensures that our efforts are informed by the perspectives of disabled people, and helps to make the issue real for non-disabled people and build their engagement and commitment. Since people with learning difficulties and people who have experienced mental ill health do not often have their own representative organisations, it can be more difficult to involve them, but it may be possible to consult them through partnerships with organisations that work with or for these people.

Different VSO programmes have chosen different starting points. For example, some programmes started by focusing on a specific impairment, typically deafness, as Deaf people are often particularly excluded from mainstream development. Our experience shows that any of the internal elements of the mainstreaming model can be a valid entry point:

- VSO India based their mainstreaming (see Chapter 5) on the initial **commitment** of their Country Director.
- For VSO The Philippines, the recruitment of a Deaf volunteer required **workplace** adjustments and also started the process of sensitisation (see Chapter 4). Similarly, a Deaf volunteer started VSO Ghana's work on disability and HIV & AIDS (see Chapter 7).
- Interacting with disabled volunteers or colleagues in the **workplace** has been an important sensitisation process for a number of other VSO programmes (e.g. VSO Namibia, VSO Tanzania, VSO Sri Lanka, VSO Thailand etc).
- For VSO Namibia (see Chapter 6), mainstreaming began with involving disabled people in the **programme** design process for a project proposal to the EC.
- **Programme** level work is probably the most common entry point for disability

mainstreaming in VSO, since this is how most programmes first come into contact with disabled people as partners or volunteers. This was the initial entry point for VSO Thailand (see Case Study 3), and for VSO programmes in Ghana, Guyana, Indonesia, Kenya, Nepal, Pakistan, The Philippines, Rwanda, Sri Lanka, Vietnam and other countries.

- DREAM-IT has seen some excellent initiatives by individual volunteers as a result of disability **sensitisation** (see Chapter 4). However, our experience in disability mainstreaming suggests that sensitisation is most effective in support of workplace or programme mainstreaming activities, rather than as an entry point by itself.

Wherever we start, mainstreaming involves working on all of these elements in a properly planned, joined-up way. As soon as we complete one piece of work, we need to review our progress so far, and plan and budget for the next step.

KEY RESOURCES

VSO Position Paper: *Including Disabled People*

http://www.vso.org.uk/Images/position_papers_including_disabled_tcm8-1602.pdf

Disability KaR: *Lessons from the Disability Knowledge and Research Programme*

<http://www.disabilitykar.net/pdfs/learn.pdf>