

The true nature of "disability" is not individuals' mere functional limitations. "Disability" is oppression, discrimination, social exclusion and restriction of participation which is socially constructed and imposed upon people who are regarded as different in terms of body functions and structures. Therefore, disabled people are neither less-able nor in-able, but are dis-abled by the society which takes little or no account of people who have different functions and structures.

This perspective on "disability" is called the Social Model of Disability, and makes the conceptual foundation of Disability Equality Training (DET). DET is a disability education programme which aims to promote understanding of disability from the Social Model perspective, and facilitate proactive actions to break disabling barriers in our society. DET takes facilitated and participatory learning approaches as its methods of training.

Liz Carr, a wheelchair-user, is Britain's foremost disability comedian, actress, writer and performer. A regular on the BBC's OUCH website (where she presents a podcast and writes a regular column). Originally a DET trainer with a degree in law she now writes and performs her own material as well as acting in others plays and comedies. There are few to compare to Liz's prodigious talents and she now regularly appears at the Edinburgh Festival. See her website at www.lizcarr.co.uk for more information.

Dr Paul Darke, is an internationally respected academic, writer and cultural critic who has written and created extensively around the issue of identity and culture. He is also the originator of Normality Theory. As an artist Paul Darke is bringing, to various art forms, new insights and exciting concepts which challenge conventional views of both art and society. A wheelchair user whose PhD is on-line at www.darke.info

Kenji Kuno, PhD, is an advisor on disability for the Japan International Cooperation Agency (JICA), and a visiting researcher of the Centre of Excellence, Nihon Fukushi University, Japan. A coordinator of the Asia Pacific Disability Equality Training (DET) Forum (www.detforum.com).



UTUSAN PUBLICATIONS & DISTRIBUTORS SDN BHD



Training Them and Us:
A Guide to Social
Equality for Society

Liz Carr • Paul Darke • Kenji Kuno



DISABILITY EQUALITY TRAINING (DET) MANUAL SERIES NO. 1



Training Them and Us:

A Guide to Social Equality for Society

Liz Carr • Paul Darke • Kenji Kuno

Disability Equality Training (DET) Manual Series No. 1

TRAINING THEM AND US

A Guide to Social Equality for Society

DET Manual Series:

- No. 1. *Training Them and Us: A Guide to Social Equality for Society*
Liz Carr, Paul Darke and Kenji Kuno
- No. 2. *Promoting Disability Equality: From Theory into Practice*
Kevin McLaughlin and Kenji Kuno

Disability Equality Training (DET) Manual Series No. 1

TRAINING THEM AND US

A Guide to Social Equality for Society

Liz Carr
Paul Darke
Kenji Kuno

Logo

UTUSAN PUBLICATIONS & DISTRIBUTORS SDN BHD

Published and distributed by

UTUSAN PUBLICATIONS & DISTRIBUTORS SDN BHD

No. 1 & 3, Jalan 3/91A

Taman Shamelin Perkasa, Cheras

56100 Kuala Lumpur

Malaysia

First published 2008

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, or otherwise, without prior permission of the Publishers, except by a reviewer who may quote brief passages in a review.

Perpustakaan Negara Malaysia Data Pengkatalogan-dalam-Penerbitan

ISBN 978-XXX-XXX-XXX-X

Copyright © Utusan Publications & Distributors Sdn. Bhd.

Printed by

UTUSAN PUBLICATIONS & DISTRIBUTORS SDN BHD

No. 1 & 3, Jalan 3/91A

Taman Shamelin Perkasa, Cheras

56100 Kuala Lumpur

Malaysia

Contents

Preface <i>Kenji Kuno</i>	viii
------------------------------	------

**Part One: Principles and Practice of
Disability Equality Training (DET)**
Liz Carr and Paul Darke

1. Introduction to DET	1
2. What DET is	2
3. Why We Need DET	3
4. DET vs Disability Awareness Training	4
5. Who Delivers DET	5
6. Who Attends DET Training	5
7. Aims and Objectives of DET	6
8. Course Length	7
9. Process of the Programme	8
10. Typical Content	9
11. Courses for Disabled People	12
12. Example of DET Courses	17
13. Sample Exercises	26
14. Disability Art Training – An Overview	34

15. Effective Action Planning	35
16. Developing Your Own Material	36

Part Two: Philosophies Behind DET: Disability and the Disabled People's Movement

Liz Carr and Paul Darke

17. What Disables People	38
18. Models of Disability	39
19. The Language of Disability	43
20. Acceptable Terminology	44
21. No to People with Disabilities	45
22. Disabled People's Movement	46
23. Issues of Independent Living	50
24. Disabled People in History	53
25. Civil Rights for Disabled People	59

Part Three: For DET Trainers: What Next

Liz Carr and Paul Darke

26. Qualifications for DET Trainers	66
27. Essential Skills	67
28. Training the Trainer Courses	68
29. Still Want to be a DET Trainer	69
30. Employment Options	70
31. Marketing Yourself	70
32. Promotional Material	71
33. Fees	73
34. Contracts	73
35. Check List and Payment	75

Part Four: Concepts around Disability and Disabled People

Kenji Kuno

36. Models of Disability	78
Introduction	78
Medical Model of Disability	83
Social Model of Disability	84
Synthesised Model of Disability	87
Differentia Model of Disability	89
Family Model of Disability	96
37. Participation	98
38. Empowerment	102
39. Social Exclusion	105
40. Capability Approach	112
Introduction	112
Key Concepts of the Capability Approach	114
Implications of the Capability Approach for Disability	118
Consideration Points of the Capability Approach	124
Conclusion	127
<i>Postscript</i>	128
<i>References</i>	130

Preface

This is the first book of a series of Disability Equality Training (DET) manuals for DET trainers. This DET Manual series is published as a part of the Project on Disability, implemented by the Japan International Cooperation Agency (JICA) and the Department of Social Welfare, Malaysia. This project, Capacity Building on Social Welfare Services for Disabled People, is implemented to promote the participation and inclusion of disabled people and the mainstreaming of disability issues in development interventions. This project is designed based on the concept of the social model of disability. DET is taken as one of the key components of the project in addition to the promotion of the independent living movement, supported employment, and self-advocacy of persons with learning difficulties. In this project, 41 disabled people from ten countries, namely, Malaysia, Thailand, Singapore, Indonesia, Nepal, Bangladesh, Pakistan, Kyrgyzstan, Maldives and Afghanistan were trained as DET trainers over the last three years.

The authors of these manuals were all trainers of this DET trainers' training, except Dr Paul Darke and Liz Carr who kindly agreed to publish their work on DET as a part of this manual series.

I truly hope that this book will provide useful information and ideas on DET. I also welcome comments and suggestions. The above-mentioned project has a website on DET (www.detforum.com) to provide and exchange information and ideas, so please do visit it.

I believe the essential element in working on disability is ‘SPICE’ (just as spices are essential to cook a delicious curry!). So, what is SPICE? It is the promotion of **S**ocial **P**articipation, **I**nclusion in the **C**ommunity, and **E**mpowerment of all disabled people. So, let us ‘SPICE up’ our work on disability together!

Kenji Kuno

Part One

Principles and Practice of Disability Equality Training (DET)

Liz Carr and Paul Darke

This section gives a basic introduction to DET, what it is, and answers some FAQs about it. This section also explains the basic principles of DET and examines how we transform knowledge of disability issues into a DET course by looking at the content, sample programmes and exercises.

1. Introduction to DET

Disability is not a 'minority' issue; government underestimates state that there are approximately 8.6 million disabled people in the UK – a 'minority' of at least 14% of the population.

The social model of disability, the basis for DET, needs to be within the reach of as many people as possible, disabled and non-disabled alike, and the Internet is an ideal way for people wishing to increase their knowledge to find the information and training they require.

In light of the Disability Discrimination Act 1995 and the Human Rights Act 2000, many public and private sector bodies have realised that their work practices and policies fall far short of fulfilling the needs, rights and aspirations of disabled people who are their clients, customers and co-

workers and that, in order to change this situation, they need to turn to disabled people to deliver quality DET.

With this growing demand for DET run by disabled people, it is hoped that this book will allow many more disabled people to learn about the social model of disability, become DET trainers and start working with organisations to help them understand the meaning of disability, identify changes in work practice, and plan strategies to implement change.

Who this book is for:

- those with little or no knowledge of DET
- those who would like a recap on their DET knowledge
- disabled people who are interested in becoming DET trainers
- those who have recently been on a DET course or have just heard the term and would like to find out more
- a DET Trainer or a disabled person who would like to become more involved
- anyone, disabled or non-disabled, possessing any knowledge of disability issues and experience of DET

2. What DET is

DET is a participatory process where people are introduced to the real issues and discrimination facing all disabled people with a view to them changing their behaviour, policies and practices.

As with other equality training, DET courses are designed and delivered by the people who have direct experience of discrimination, i.e. qualified disabled trainers who experience disability as a form of social oppression and therefore truly understand the reality of living in a disabling society.

DET is not some new fangled trendy idea; it has been in existence in some form or other since the early to mid-eighties and its history is rooted firmly in the Disabled People's Movement. Based on the direct, collective experiences of disabled people, recognising that the problem is one of institutionalised discrimination, DET puts emphasis on 'action':

making changes within working environments and society, by looking at the barriers within the workplace and encouraging participants to form a plan of action to remove the barriers.

DET is about:

- The social model of disability;
- Disabled people leading the training;
- Examining the barriers faced by disabled people in society;
- Questioning stereotypes, myths and misconceptions about disabled people;
- A commitment to change.

DET is not about:

- Making non-disabled people feel guilty;
- Non-disabled professionals discussing disabled people's lives;
- Disabled people recounting their life stories;
- Simulating physical, sensory or mental impairments;
- Giving information about specific medical conditions.

3. Why We Need DET

For many years, trainers, often non-disabled trainers, have been delivering disability awareness courses often from an individual perspective as a way of demonstrating the different needs of people with a particular impairment. Heightening awareness usually takes the form of trying to change people's attitude towards disabled people.

One way of achieving this is through 'simulation' exercises. For example, participants are blindfolded so they know what it feels like to be blind or they use the wheelchair for a few minutes to know what it is like for someone who is a wheelchair user. This individualises disability by focusing on what it is like not to see or walk and trivialises the discrimination and barriers which disabled people experience.

For disabled people to have any chance of participating in their own right within their community, we have to change more than attitudes, we have

to change the environment, systems and institutions within which we live. This can only be achieved by understanding the issues which affect our lives from a social model perspective, addressing the barriers that exist and changing policies and practices which exclude us.

A key principle of DET, therefore, is disabled trainers as experts and role models working to facilitate the change in perspective and behaviour of course participants.

DET moves beyond winning hearts and minds and asking non-disabled people to see the individual but instead demands that organisations recognise disability as an equality issue, making parallels with other marginalised groups within society.

4. DET vs Disability Awareness Training

Although some people who run courses use these terms interchangeably, there is a big difference between disability equality training (DET) and disability awareness training (DAT):

DET	DAT
disabled trainers	non-disabled trainers
focus on discrimination	focus on impairments
disabled people as experts	professionals as experts
direct experience	simulation
rights and equality	'special needs' and etiquette
changes in behaviour/action	changes in attitude
based on SM of disability	not based on the SM
accountable to DPM	not accountable to DPM

SM = social model

DPM = Disabled People's Movement

5. Who Delivers DET

Disabled people with a social model perspective to disability

It is not enough to be a disabled person and it is not enough to understand the social model of disability but it is a core principle of DET that all courses are run by disabled people with a solid understanding of the social model of disability and the Disabled People's Movement.

Disabled people with some level of group work/training skills

Training and group work skills are also important but it is worth noting that the traditional way of training may be inaccessible to some disabled people. If we take a social model approach to training, we can see the barriers to training as problems which we can solve through creative and accessible solutions: e.g. short courses, regular breaks, adapted equipment, use of images, words or drama to facilitate learning.

The barriers disabled people face in education, training and employment need to be recognised so they do not prevent a person from missing the opportunity to become a trainer.

DET trainers may be members of organisations of disabled people, of DET organisations / groups / forums or freelancers / individuals.

6. Who Attends DET Training

Anyone – disabled or non-disabled – can attend a disability equality event. Public, private and voluntary bodies may commission training from an organisation or individual for a cross group of employees or perhaps for a specific group.

There are unfortunately few training opportunities for the general public who do not have access to courses through work or other involvement.

DET is mostly associated with the training of non-disabled people but it is essential that there are DET or personal development courses (PDCs)

for disabled people only. Such courses will be founded on exploring and recognising the commonality of direct experiences and lead participants to examine the issues of disability equality in a safe and supportive disabled persons only environment.

Personal development courses are usually conducted by organisations run and controlled by disabled people.

7. Aims and Objectives of DET

Whilst individual styles and methods may differ, DET training should have core aims which are consistent with the Disabled People's Movement. For example, DET is designed and delivered by disabled people to enable participants to understand 'disability' from a social model perspective and to commit to removing disabling barriers.

The core aims of DET must be non-negotiable but beyond that, it is good practice that courses are always tailor-made to suit the objectives and needs of the people buying in / requesting the training. Following is a sample set of aims and objectives from the London Boroughs Disability Resource Team guide to DET.

Aims

A DET course will enable participants to identify and address discriminatory forms of practice towards disabled people by encouraging an understanding of disability issues and their implications. DET aims to initiate action towards creating a society in which disabled people have the right, opportunity and choice of realising their potential as fully functioning citizens.

Objectives

- To reach a social as opposed to an individual/medical model of disability;
- To challenge some of the common myths and assumptions surrounding disability and disabled people;

- To demonstrate the practical application of equal opportunities as policies for disabled people within the immediate area of work of course participants;
- To recognise that disabled people may experience multiple types of oppression and that specific strategies need to be developed to challenge this form of discrimination;
- To formulate an action plan of constructive changes which participants can make to their work situations and personal lives and that will contribute to the gathering momentum for change in the social, economic and political position of disabled people;
- To equip participants with a practical understanding of the models of disability, enabling them to recognise discriminatory language and images which perpetuate the oppression of disabled people.

8. Course Length

A minimum of 2 days is recommended to conduct an effective DET. A 1/2 day follow-up 3-6 months later is suggested good practice, allowing time to recap on core issues and for feedback of action plan changes and commitments. These, of course, are ideals and in the current training climate of best value and damage limitation, organisations are keen on disability training but are less keen to release their staff for more than a few hours.

Requests for 2-hour sessions are more likely than for 2-day training events and follow-up sessions are a real luxury; it is up to the training organisation or individual trainer to decide on minimum time requirements for delivering effective DET.

Arguments for delivering DET regardless of the time period include:

- something is better than nothing;
- let's get our foot/wheels in the door and see what it leads to;
- if we don't do it, someone else will anyway;
- 2 hours or 2 days, if they're going to get it, they'll get it.

Arguments against conducting DET in less than the ideal time period include:

- they just want to do a couple of hours and tick the disability box;
- it's nothing more than tokenism;
- there's no real time/intention for change;
- a little knowledge is a dangerous thing.

9. Process of the Programme

DET courses are designed to allow incremental learning throughout the session and it is this building block approach which allows participants to build up their understanding of these new issues by using their existing knowledge, new information and a structured programme.

The first part of a session, whatever length the course, is the time for participants to grasp the social model philosophy. Ideally, a minimum of half a day should be devoted to redefining disability: it takes time to 'unprogramme' people after a lifetime of living within a medical model world.

Redefining disability is an ongoing process throughout the course. Examples should be given as to how disability is created and maintained in society by barriers. Images, language and media portrayals could be examined with 'positive' alternatives presented. Every negative demonstration of discrimination should be countered by a positive real life solution.

At end of the first day or the end of the session, participants should be able to apply some of the knowledge gained to a short exercise/action plan relating to themselves and their jobs. An experience common to all forms of equality training is that at this point in an event, it is quite likely that trainees may feel overwhelmed by the enormity of the issues. This is to be expected when exposing societal oppression and the part an individual participant would have unconsciously played in it. Ideally, therefore, a consecutive second day could allow you to deal sensitively and

productively with this new knowledge rather than leaving participants high and dry.

A second day would allow participants to look at their area of work in detail, providing them with tools to identify the areas of discrimination and to challenge them. Re-affirming the social model, situating disability within a rights based framework, including rights, and drawing parallels and links with other oppressed groups would be other suitable topics for a second day of training. Relevant rights, legislation and organisational policies would have a significant slot and provide a basis for action planning for change so that by the end of the course all participants are equipped with the knowledge of not only what they must do but also why they should do it.

10. Typical Content

There is no standardisation in the content of DET courses. However, all DET will include an exploration of:

- the social and medical models of disability;
- disabling barriers;
- disability as an equality issue;
- language and images of disability;
- the disabled people's movement;
- potential for change through action planning.

The following more detailed headings relate to the typical content of a DET session:

Ground Rules

It is good practice in all training events to apply a set of ground rules which participants agree to observe during the course to allow for a safe, inclusive and productive learning environment which offers everyone equality of participation.

Warm-up

A simple but important part of any session where everyone has an opportunity to contribute and be heard or be involved in the activity.

Disabling Barriers

An opportunity for participants to explore what disability means in terms of the attitudinal, environmental and institutional barriers experienced by all disabled people, e.g. negative attitudes, lack of accessible information, lack of access, discrimination in transport, housing and other services.

Social vs Medical Model of Disability

In order to understand the processes that result in inequality, discrimination and 'disability', disabled people have redefined disability using their direct experiences as the basis for the social model disability. One of the first and ongoing tasks of an equality trainer is to move people away from the traditional medical model of disability to the social approach.

Self-Organisation of Disabled People

The history of the Disabled People's Movement, the difference between 'of' and 'for' organisations and topical issues and campaigns.

Terminology

Words and phrases used to describe disabled people and the impact these have on attitudes to, and the lives of disabled people. It is essential that participants explore their understanding of language and the images and ideas this holds for them – it is difficult to separate language from ideas and images.

Rights and Equal Opportunities

Using the social model, it is clear where discrimination takes place and what measures need to be taken to eradicate it. Disability is an equality and a rights issue – the social model acknowledges that it is not the individual's problem but the failure of society to recognise the rights of disabled people which causes inequality.

Oppression

To recognise that disabled people may experience multiple types of oppression and that by understanding disability from a social model context, disabled people can make links with other groups whose biology has been used to justify their exclusion, e.g. black people, women, gay men and lesbians.

Stereotypes and Image of Disabled People

Image of disabled people in society, how disabled people are viewed and portrayed in the media, in particular charity representation of disability balanced by a more accurate picture of disability as illustrated in disability arts and writing verse, photography and music of disabled people themselves.

Current Disability Issues

It is important to be able to bring current issues of importance and relevance to the awareness of participants, not least to illustrate the relevance and importance of DET to real life and the daily experiences of disabled people.

Action Planning for Change

To give participants the opportunity to consider how their attitudes, actions and work practices can be easily altered to reduce discrimination and barriers against disabled people.

Evaluation

The training, trainer, venue, feelings of the participants, relevance, learning, good and bad of the training are all usual topics to evaluate following a session.

Depending on the requirements of the organisation requesting the training, courses may be more focused on specific areas of relevance. Additional topics may include:

- Disability Discrimination Act 1995 (DDA);
- independent living and 7 needs;
- user-involvement and consultation;
- direct payments and personal assistance;
- inclusive education;
- employment issues – recruitment, selection and retention.

11. Courses for Disabled People

Background

It is likely that disabled people will be participants in DET courses; sometimes obviously but more often not as many impairments are hidden and non-evident. This is very different, however, from delivering courses which are only for disabled people. As with other groups discriminated against in society, disabled people have recognised the importance of joining together in disabled people only space, to learn, discuss and redefine disability from a point of direct experience.

This ‘politicisation’ of disabled people around the core understanding of the social model of disability is rooted in our history and in the history of the development of the disabled people’s movement when informal networks of disabled people gathered together to discuss their experience of disability and the seeds of the social model were sewn. This shift from an individual experience to a collective identity as a disabled person often comes from such informal contact with other disabled people. However, some groups may conduct courses such as ‘personal development’, ‘empowerment’, ‘disability issues’, and ‘the personal to the political’ training.

Content

The courses are not about how ‘bad’ our impairments are, or whether we are better/worse than anyone else; they are instead about sharing our experience as disabled people – both positive and negative and in doing so, recognising the similarities and shared barriers and discrimination we experience regardless of our different impairments. Through a programme

which moves us from our personal experience to a shared understanding of the social model of disability, these courses provide a liberatory framework so we can remove the blame imposed by the medical model and place the responsibility squarely on society where it belongs.

Typical issues covered include: barriers and solutions, the social/medical model of disability, our history, media, imagery, language, attitudes and assumptions, fight for our rights, the law, independence versus care, independent living, the Disabled People's Movement and other civil rights issues.

Whilst the contents of courses for disabled people and DET are similar, there are inherent differences due to the fact that the content is directly about the lives of disabled people. An interesting example of discrimination for non-disabled people could be a painful real life experience for disabled people. Thus the responses and the consequences will be completely different.

Sample Aims, Objectives and Programme

'Understanding Disability' – a 2-day course for disabled people

Aims

To provide disabled people with a practical and accessible understanding of the social model of disability through sharing direct experience, exploring common barriers and tutor input.

To equip disabled people with the information, skills and confidence to re-evaluate their life experiences and opportunities from a social model understanding of disability.

Objectives

- To share common experiences
- To discuss and identify the barriers disabled people experience
- To gain an understanding of the social model of disability
- To recognise and explore the rights of disabled people

- To explore positive and negative words for and images of disabled people
- To learn about the Disabled People's Movement and its history
- To gain an understanding of independent living
- To recognise individual skills, strengths and resources
- To develop short-, medium- and long-term goals
- To identify future opportunities, training and information needs

The only qualification for this course is that participants define themselves as disabled people as this course is open only to disabled people.

Day 1

Time	Contents
09.30	Introductions and warm-up
10.00	Hopes and concerns Big group – one hope and one concern – flip chart
10.15	Ground rules
10.45	Disability is ... One word or short sentence that sums up what disability means to you. Flip chart. Is this list unique to only this group? This is our starting point – we are going to look beyond our immediate situation and at our history and connect with other disabled people.
11.15	Coffee
11.30	Barriers exercise 3 groups: Attitudes Environment (physical/information) Systems/services (education system)
12.15	Video – A different approach
12.30	Social and medical model flip chart presentation
01.00	Lunch

02.00	<p>Images of ourselves</p> <p>Where do we see disabled people in the media? How are disabled people portrayed by non-disabled people?</p> <p>Taking a closer look at charity advertisements/campaigns</p> <p>Charity and negative images – Aliens have landed on planet Earth and the only information they have are charity advertisements/campaigns/posters. 2/3 groups look at charity images and discuss:</p> <ul style="list-style-type: none"> – What impression of disabled people will the aliens get from these? – What are disabled people like? Who are the disabled people? <p>Feedback – Society's views of disabled people are shaped by these images and affect our self-esteem.</p> <p>Celebratory images – In same groups, list feelings/responses to examples of self-representation</p> <p>Feedback – Why are the feelings and responses so different?</p>
03.30	Coffee
03.45	Introduction to the Movement and History of Disability – Video and Discussion
04.30	Close

Day 2

Time	Content
10.00	Welcome and recap
10.15	<p>The charity issue</p> <p>Think of a disability charity (flip chart): What do they have in common?</p> <p>Impairment specific ... Run by non-disabled people for disabled people ...</p> <p>History of charity – set up to maintain institutions – separate us from each other – competing for funds.</p>

Are there any organisations for all disabled people? Has anyone heard of the BCODP* ...

Are the major disability charities, none of which is run and controlled by disabled people, in any way accountable to them? Look at other examples of white people claiming to represent black people's interests; men speaking for women ...

10.45 Language – Does it matter?

11.15 Coffee

11.45 Independent Living: What does this mean for disabled people?
Whole group discussion
What do we need to live independently?
Groups and feedback as 7 needs.

12.30 Lunch

01.30 Dare to be you!
Individual opportunity to explore skills and qualities

02.15 Personal action plan
What do you want to achieve in life? What are the barriers/solutions?

03.00 Coffee

03.15 Discrimination in our lives
3 groups each discuss a time in their lives when they felt discriminated against:
– Medical profession
– Leisure
– Employment
– Service provision

Will not be shared with large group. Take one example and discuss solutions if tackled collectively – group solutions, feedback to whole group.

Feedback – There is a need for a collective response to discrimination – too difficult to fight discrimination on our own. We can change things by coming together ... disability movement ...

04.15 What next: Discussion and information Exchange

04.30 Closing Thoughts & Evaluation

05.00 Goodbye

*BCODP: British Council of Disabled People

12. Example of DET Courses

The following sample aims, objectives and timetables are from training courses delivered in recent years. They should give an idea of how the issues and content can be put together to form a training programme and also an idea of the variety and potential of DET. More general information on how to design a training programme is available in the section entitled 'Sample Exercises'.

Example 1: One-day DET for staff working with young disabled people

Aims

To develop an understanding of the social and medical models of disability and their relevance to developing anti-discriminatory practices in your organisation.

Objectives

- To understand disability as a form of social oppression
- To identify terminology related to disabled people
- To explore the ways in which imagery of disabled people perpetuates oppression
- To explore and challenge the charitable ethos which surrounds disabled people
- To develop action plans which relate to short-term objectives

Time	Content
10.00	Welcome and introduction
10.30	Sticks and stones ... (words associated with disability/disabled people)

10.45	Names will never hurt me ... (positive/negative words and definitions)
11.15	Coffee
11.45	Never ending story ... (causes of disability and impairment)
12.15	Every picture ... (images exercise)
12.45	Lunch
01.30	Freedom ... (barriers and solutions to independent living)
02.00	Ring in the changes ... (making change happen – barriers/solutions)
02.30	A change for the better ... (completing action plans)
03.15	Questions and Answers / Evaluation / Summing up
03.30	End

Example 2: One-day DET for local authority staff

By the end of the course, participants will:

- gain an understanding of the importance of appropriate and inappropriate disability terminology and imagery;
- be able to differentiate between social and medical models of disability;
- be able to identify work practices and policies that are both consistent and inconsistent with the social model of disability and the Disability Discrimination Act;
- have an understanding of how disabled people may be allowed to control their own lives.

Time	Contents
10.00	Introduction / Ground rules / Aims and objectives
10.30	The importance of words – pairs and feedback
11.00	Break
11.15	Images of disability – 3 groups

12.00	Power and control – small groups
12.30	Lunch
01.30	Power and control – feedback
01.50	Independent Living and the 7 Needs – group exercise
02.20	Disability Discrimination Act 1995 – presentation and questions
02.45	Break
03.00	Identifying barriers in your workplace (access, attitudes and policies)
03.45	Evaluation
04.00	Close

Example 3: Two-day programme for social service staff

Aims

For workers in social services settings to understand the importance of the social model of disability in their work and to identify strategies to influence and change current work practices with regard to local disabled people who use these services.

Objectives

By the end of the course, participants will have:

- Investigated attitudes towards disabled people and concepts of disability
- An understanding of the medical and social models of disability and disability terminology
- Established the links between the oppression of disabled people and that of other groups
- Explored the concept of independent living and the implications for professionals working with disabled people
- An understanding of the notion of choices and rights and how it all fits into good practice within the community care legislation
- Identified real ways of implementing good practices following the social model of disability into their daily work practice.

Day 1

Time	Content
10.00	Introduction and warm-up
10.30	Where does disability come from? Exploring the real problem (small groups)
11.15	Coffee
11.30	Redefining disability – video and comments
11.45	Models of disability – analysing conflicting views of disability – presentation
12.30	Disabled people self-defined, ‘in our own words’ – examination of materials
01.00	Lunch
02.00	Images of disability – various workshops exploring images of disabled people
03.00	Coffee
03.15	Terminology and labels – Why so important? A different approach (group work)
03.45	Community care and the models of disability – group exercise redefining assessment questions and practices within a social model context
04.30	Close of day 1

Day 2

Time	Content
10.00	Warm-up: Empowerment through the social model – group exercise
10.30	Case study to understand the links and parallels with other oppressed groups
11.15	Coffee

11.30	Independent Living vs Care – wordstorm + small group exercise + feedback
12.15	Examples of good practices – role-play pairs
12.45	Lunch
01.45	Rights and Legislation – presentation and practical application exercise
02.45	Advocating for change – video and discussion
03.15	Coffee
03.30	Action plans – individual and work group approach
04.20	Evaluation of course
04.30	Close of course

Example 4: Course outline for one-day DET

Aims

- To dispel some of the myths and assumptions surrounding disability and disabled people
- To reach a social as opposed to a medical model of disability
- To explore the barriers disabled people face and to find solutions
- To develop practical action plans in order to implement change

Course Content

- True or false
- Some facts, figures and information about disabled people and discrimination
- Disability terminology
- Language and terminology – why it is important to understand what is acceptable/unacceptable.
- Barriers to equality
- Workshop highlighting the barriers disabled people encounter with an opportunity to discuss solutions
- Social vs medical model of disability

- Exercise exploring the differences between the traditional view of disability – the medical model, and the view disabled people have adopted – the social model
- Followed by a discussion on why the latter is fundamental in working together to ensure full and equal participation of disabled people in society
- Workshops
- Opportunity to explore various disability issues, for example, the role of charity, imagery and independent living, through a series of participatory exercises
- Action plans
- Chance for participants to put the day's lesson into action by applying it to their work and lives

Example 5: Half-day DET course

Aims

- To examine the barriers that disabled people experience from a social as opposed to a medical model of disability
- To develop a practical understanding of disabling and empowering language surrounding disabled people
- To identify opportunities and responsibilities for individual and organisational change

Time	Content
09.30	Introduction and welcome
09.45	Disability means ...? A chance to explore how much we really know about disability and disabled people
10.45	Coffee
11.00	Disabling barriers/enabling solutions A workshop highlighting the barriers disabled people encounter with an opportunity to discuss solutions and explore the difference between the traditional view of disability – the medical model and the social model.

12.00	Language – does it matter? An opportunity to discuss the importance of terminology and to explore the difference between words used to describe disabled people and their experiences.
12.30	A change for the better. A chance for participants to put the day's lesson into practice.
01.00	Farewell.

Example 6: One-day DET/DDA course

Aims

- To increase understanding of the discrimination faced by disabled people
- To examine the effects of the Disability Discrimination Act (DDA) and its ability to address this discrimination

Objectives

- To understand disability as a form of social oppression
- To be able to identify and tackle the obstacles and barriers which prevent disabled people from leading independent lives
- To understand the scope and limitations of the Disability Discrimination Act in relation to the rights of disabled people

Time	Content
10.00	Introduction: Ground rules/aims and objectives/warm-up exercise
10.30	What is a disabled person? – pairs
11.00	Social and medical models of disability – presentation and discussion
11.30	Break
11.45	Definition of disability in the DDA: presentation and terminology exercise

12.30	What is discrimination? – pairs
01.00	Lunch
01.45	Disabling barriers – small group exercise
02.15	The Disability Discrimination Act 1995 – presentation and questions
03.00	Break
03.15	Theory into practice – Beyond the DDA
03.45	Evaluation
04.00	Close

Example 7: Course outline for one-day DET/DDA

Aim

To increase knowledge of the Disability Discrimination Act 1995 and its implications.

Objectives

- To gain an understanding of the meaning of disability in relation to discrimination
- To impart key features of the DDA in relation to employment and goods facilities and services
- To consider the implications of the act for employees/employers and/or providers of goods, facilities and services

Course Content

- Understanding disability
- Introduction to the social model of disability and some facts and figures on disabled people in the UK. An opportunity to put the DDA in context.
- Video
- Short introductory video highlighting key features of the DDA.
- The Disability Discrimination Act

- ‘Upfront’ presentation using the OHP to introduce the three major components of the act:
 - Prohibition
 - Reasonable adjustment
 - Justifiable discrimination
- Reasonable adjustment
- A small group workshop examining reasonable adjustment in greater detail. Using realistic examples, participants will be asked to identify reasonable adjustments to be made.
- Linking theory to practice
- Workshop integrating learning to work practice in order to develop clear commitment to personal, professional and organisational action to ensure compliance with the DDA.
- Opportunity to produce action plans and a checklist of good practices.

Example 8: Half-day DET/DDA course

Aims

- To gain an understanding of the meaning of disability and current disability issues
- To impart key features of the DDA in relation to employment and service provision
- To consider the practical implications for employers and service providers to take the training forward

Time	Content
01.00	Introduction
01.15	Understanding disability
01.50	What is disability?
02.00	The medical model says ...
02.30	Coffee
02.45	DDA presentation and questions

03.15	Reasonable adjustments in your workplace
04.00	Links to practice
04.20	Evaluation
04.30	Close

13. Sample Exercises

While the sample programmes give an idea of the process, timing and typical general content, this section includes some basis sample training exercises.

Many DET trainers use similar methods and techniques and some of the following are commonly used exercises which should give you an idea of how to go about designing your own or adapting existing exercises. There are also some sample exercises in the course programme for ‘understanding disability’ and, in the next section, general tips for designing training are discussed.

Finally, a warning against any method which involves participants imagining what it must be like to have an impairment as this individualising approach belongs in the hands of the disability awareness trainer. It is not performed by any competent DET trainer.

Warm-ups

A warm-up may be a game to help participants relax. It may be an opportunity for people to introduce themselves and for trainers to gain information about the group, e.g. the different job titles/roles of people, level of existing knowledge, hopes and fears or previous training attended.

Ground Rules

You can word-storm group ground rules, discuss in groups and then provide feedback, give a prepared list of ground rules which can be read out loud or you could write a RESPECT model on the flip chart and

go through it, e.g. responsibility, energy, support, punctuality, equality, confidentiality, talk, one at a time.

Barriers Workshop

This exercise can be done with small and large groups. It is a useful way of drawing out and documenting the knowledge that people already have. By drawing on their own perceptions of how disabled people are discriminated against, participants can build up a list which begins to identify the extent of this discrimination. It therefore becomes clear where the real problem of disability lies, focusing people's thinking and leading them to define disability in a social context rather than by impairment.

- Group 1: Word-storm the organisational barriers which disabled people experience (e.g. legal system, education, class structure)
- Group 2: Word-storm the environmental and access barriers which disabled people experience (e.g. environment, buildings, information)
- Group 3: Word-storm the attitudinal barriers which disabled people experience (e.g. negative attitudes and assumptions)

Rights Exercise

In groups, consider and write down your responses to the following:

- What do we mean by rights?
- In a general sense, what are considered to be the rights of people in society?
- What are the differences between civil rights/human rights/entitlements? Can you give an example of each?
- What blocks and barriers may stop disabled people from having these rights?

In large group give feedback and discuss.

Example of Social/Medical Model Presentation

Many DET trainers develop their own way of introducing the social and medical models of disability to participants. The following is an example

of the types of issues you may wish to raise when presenting the models in training.

Models are developed in order to understand the way society works. Disabled people developed the social model in order to challenge the view that we are in a constant state of illness and that it is our impairments/bodies/minds and senses which are the problem – the medical or individual model of disability.

Describe the differences in the models in a basic way and ask the group questions to draw out the meaning and differences between the models.

Examples may include:

- What does the medical model concentrate on? What is it trying to achieve – its aim?
- What does the social model concentrate on? What is it trying to achieve – its aim?

You may then sum up and clarify the differences in the models.

Some Social/Medical Model Discussion Points and Group Work Ideas

The following are some questions which you could ask small groups or the whole group to stir participants to question their common knowledge about disability.

Why not draw up 2 or 3 questions on a topic such as education and make this into a workshop where a small group steps aside to discuss the questions and then returns to tell the others what they have discussed?

Each small group could have a different topic to consider, e.g. the role of charity, media, independent living, other oppressed groups.

- Think about where information is found and the barriers to accessing the information – e.g. does the library have books and information on tape, where would you get the information translated into braille?
- Why are disabled people segregated?

- Why do disabled people travel in vehicles marked ‘ambulance’?
- Why are so many of the buildings difficult for disabled people to enter?
- Who designs buildings?
- Why do you think wheelchair users are expected to be accompanied when they visit a theatre or cinema?
- Are there other leisure facilities that are difficult for disabled people to use – e.g. swimming pools, clubs, football fields?
- What would need to change for disabled people to be fully successful in mainstream education? Think about access, attitudes of parents/children/teachers/governors, training and policy issues.
- Why are disabled people not expected to succeed in employment? Why is it so hard for them to gain equal access to employment? Think about the recruitment process, attitudes of employers, etc.

Redefining Disability

Part 1: In pairs/small groups, get participants to consider:

What is disability?/What is impairment?/Who are disabled people?
Flip chart feedback and distinguish between medical/social model responses.

Part 2: In big group, split (or have two) flip chart(s) and list:

causes of impairment

accidents
medical negligence
violence
acts of God
hereditary
self inflicted
stress
wars

disability means ...

segregation
discrimination
inaccessible transport
lack of information
poor education
prejudice
poverty
negative assumptions

Using the answers given (as above) in the big group, consider the following: in a world where there is the political will and the resources, go

through ‘disability means ...’ and list and cross those we can eliminate (given time, money and political will). Now go through ‘causes of impairment’

Most, if not all, of the barriers under the ‘disability means’ heading will be removed but few, if any, of the causes of impairment will be removed. Ask participants what conclusion we can draw from this exercise. We will always live in a world where impairment is natural yet we need not live in a disabling world. Rather than spend time and resources to eliminate impairment, we can – should – work together to break down the disabling barriers which prevent us from taking part in ordinary, everyday life. This is the social model of disability – focus away from the individual, responsibility in the hands of society and promote change, equality and inclusion.

Part 3: Using all this learning and new information, in same pairs/groups as before, come up with a simple social model definition of disability by completing the sentence: Disability means ...’ or ‘The medical model says ...’

Change these statements from the medical model problems into social model solutions.

Example:

“I can’t go out with my friends because my cerebral palsy prevents me from getting on the bus.” (medical model problem)



“If the bus was accessible, I could go out with my friends.” (social model solution)

- (1) I can’t go to the same school as my friends because I can’t get up the steps in my wheelchair.
- (2) I can’t read books, magazines or newspapers because I can’t see.
- (3) I can’t go to my local cinema because my spina bifida means I am a fire hazard.
- (4) I can’t be on the youth club committee because I can’t hear.

- (5) Because I can't speak clearly, I can't make friends.
- (6) Now try and think of your own examples.

Empowerment through the Social Model

In pairs or small groups discuss the benefits of viewing disability in a social model way. Why is a social model definition of disability positive for disabled and non-disabled people? Flip chart benefits.

Language

In a large group, word-storm all the words that come to mind when you hear the word 'disability'. Discuss language issues before moving on to the second part of the workshop. In small groups, consider the following pairs of words:

- wheelchair bound/wheelchair user
- care/assistance
- suffers from .../person with ...
- carer/personal assistant
- disabled person/person with a disability
- able-bodied/non-disabled

For each pair, consider: Is there a difference? Does it matter? Discussion and feedback.

Media Images

List examples of positive and negative images of disabled people under each of the following headings:

GOOD / BAD

- Books
- Films
- TV
- Advertisements
- Charity advertising

In groups, provide participants with a selection of charity images of disabled people and ask them to consider:

- * what image of disabled people do the texts and pictures convey?
- * what emotions or attitudes do the advertisements exploit?
- * what is the purpose/s of the advertisements?

Stereotypes of Disabled People

Below are 8 of the most common media stereotypes of disabled people. For each, list examples of a book, advertisement, film, TV or radio programme which show disabled people in this stereotypical way:

- Pitiable and pathetic (e.g. Children in Need/Tiny Tim in Dickens' Christmas Carol)
- Objects of violence (e.g. Whatever Happened to Baby Jane)
- Sinister or evil (e.g. Richard III/Freddy from Nightmare on Elm Street)
- Supercrip/Triumph over tragedy (e.g. newspaper articles/Heidi/sports coverage)
- Laughable/Comic (e.g. Mr Magoo/Hear No Evil, See No Evil)
- Chip on shoulder (e.g. One Flew over the Cuckoo's Nest)
- Burden/Outcast (e.g. Snow White and the 7 Dwarfs/Beauty and the Beast)
- Non-sexual/Incapable of having relationship (e.g. Lady Chatterley's Lover/Coronation Street)

Images of Disability

The following prompts could be used to generate whole or small group discussions around images of disability:

- Where do we see disabled people in the media?
- How are disabled people portrayed?
- What kind of images is used? What type of language?
- What messages about disabled people do you get?
- Where are these attitudes/stereotypes from?
- What input, if any, do you think disabled people had in this process?

- How much do you think negative attitudes towards disabled people is generated by media coverage?
- Are disabled people getting representation that is fair, equal, free from stereotyping, according dignity?

Explore how disabled people are portrayed/represented in society. Look at where information about disabled people comes from, who is in control of it, who defines what language is used and why. Aim at an understanding of the way in which language and imagery can be very oppressive, but also very positive and powerful. Look at powerful, active images of disabled people that contradict the tragedy/fear/supercrip stereotype.

Evaluation

Two common ways of gaining initial feedback are a quick round-up at the end of the training asking participants what they learnt/enjoyed/disliked, and the filling up of 'happy sheets' by participants. However, more meaningful evaluation methods may focus on the relevance of the training during the weeks following the course.

Trainers may use their own forms, training organisations/networks will most likely use their own evaluation methods or the purchasers may prefer to use their in-house forms.

A sample happy sheet for the end of the course may ask the following questions:

- Which particular session did you find useful and why?
- Which particular session did you NOT find useful and why?
- What has been the single most important aspect of the course for you?
- Is there anything you think should have been covered that wasn't?
- What action will you personally take in order to apply the training in your work?
- Other comments

14. Disability Art Training – An Overview

Disability art training is essential for all arts, artists and arts funding bodies as it is something which few people understand and is becoming a dominant form of arts culture for disabled people.

Disability art is a new challenge to traditional art thinking and practice which is both a major step forward in the understanding of disability and in the use of art in understanding precisely what disability is (not impairment).

Disability art is very different in conception from what disability and art is, and in comparison to what art therapy is. Key distinctions need to be made so that all people involved in arts fully understand what they may be saying about disability and art *per se*. It is not about creating a hierarchy but about facilitating a more effective and comprehensive understanding of what one is precisely saying as one says it. We often use the terms interchangeably when they are very different in process, practice and intent.

Disability art is a particular use of art practice, process and philosophy that is intrinsically entwined with the philosophy of the social model of disability. It uses art to explore what disability is: the result of social processes; it has nothing to do with the individual pathology or the coping mechanisms of individuals. It is not about facilitating their understanding and comprehension of their own impairment. However, it may well be used to facilitate an understanding of the social model of disability.

Art therapy, on the other hand, is purely about doing art for therapeutic reasons. It is about facilitating an individual in learning to cope and understand his own psychological situation in relation to any pathological processes that may be inhibiting his developmental processes as either an individual or in relation to a particular focus group (familial, for example). Often, and this is a major criticism of it in relation to disability, it places disability within the individual and reinforces the false idea that disability is a pathological condition (which it is not; that is, to be more precise, an impairment).

Art and disability is merely art by disabled people that has neither a therapeutic nor a political or social dimension to it.

The distinction is for the sake of clarity and not to articulate either an hierarchy or a negation of one form in relation to another.

15. Effective Action Planning

Comments relating to the effectiveness of DET sometimes include:

- “I’m powerless to change things.”
- “Already overworked, I’ve now got more to do.”
- “I know a bit more, can tick the disability box.”
- “It’s just tokenism and won’t lead to real change.”
- “It’s not relevant to me or my job.”
- “It’s not me that needs this but my boss.”

Such comments are justified if there is no real product or change as a result of the course and if participants are left with new ideas, frustrations and enthusiasm but without guidance and support. DET courses can demonstrate the barriers and discrimination that exist for disabled people but cannot effect any fundamental change unless those involved in the training process at all levels commit themselves to a programme of action. For this change to begin to happen in DET, it is essential that there is a structure within which it can take place.

Therefore, every DET course should devote a period of time to developing a disability action plan that is relevant and achievable at both the personal and organisational levels. Trainers can use their expertise to identify realistic goals and make appropriate referrals for further information or consultation so as to ensure successful completion of participants’ action plans. Without action, training is pointless and any effects or good intentions will be lost.

A written action plan may include the following headings:

- Subject: the broad area you have picked out for improvement;

- Goals: agreed specific targets you wish to achieve;
- Problems: barriers you are going to encounter;
- Solutions: how to deal with the barriers;
- Activities: list, sequentially, steps to bring about the change;
- Time: indicated time period steps (specific dates if possible).

Short-term action plans for change should be SMART (specific, measurable, achievable, realistic, time limited).

16. Developing Your Own Material

Potential material is everywhere, e.g. websites, newspaper cuttings, magazine articles, leaflets, advertisements, TV and radio programmes. Cut things out, keep things you see, keep your video at the ready and a tape recorder available for recording radio programmes. A clip of a TV coverage or a magazine article may become the basis for a whole exercise where questions are asked and participants consider the issues raised. It is important to keep updating information and resources on disability.

Always work from the aims and objectives as the starting point rather than churning out the same materials regardless of the aims and objectives. If you find something that works – great, but as a starting point, always ask yourself, “What do I want participants to know and learn by doing this exercise?” Once you are clear about the outcomes of an exercise, then you are clearer about how best to ensure you meet them.

Simple can often be best. New trainers in particular have a tendency to want to dream up the most elaborate and clever techniques when simply asking people to discuss in pairs, “What disables people?” can lead to detailed responses, allowing them to examine the models of disability!

Many trainers use similar materials and similar approaches to exploring the core issues of DET. As long as you meet the aims and objectives of the training, don't worry if other people do things the same way as you do or differently. Each trainer brings his own style and strengths which distinguish trainer from trainer.

Sharing ideas and using tried and tested materials which meet the aims and objectives of DET are a good idea. The reality that training is a career, however, may lead some trainers to copyright materials while others may be happy for their work to be shared, copied and used. As a matter of good practice, therefore, you could ask the trainer permission to use and adapt his ideas and methods.

You could use material that someone else has prepared and designed; for example, you can buy ready made training packs from organisations of disabled people and mainstream training providers. If you use materials that you have not designed and do not personally 'own', you usually need to adapt them and add your own style in order to feel comfortable using them and for the materials to be as effective as possible.

Do not be afraid to try new things; just because you have always done something one way does not mean it is the best way!!!

The best way is one which is effective in passing on the information and enabling the participants to learn about disability equality: for example, by using more 'creative' training methods, participants could show the differences between the models of disability through pictures, drama or song.

Part Two

Philosophies Behind DET: Disability and the Disabled People's Movement

Liz Carr and Paul Darke

This section provides a basic introduction to some of the principle beliefs behind DET and the growing social empowerment of disabled people. It places DET within a broader social context.

17. What Disables People

To really understand the importance and basis of DET, we need to look at what we mean when we talk about disability. Who are disabled people and what is it that disables people?

The Disabled People's Movement makes a key distinction between impairment and disability.

Impairment: What is 'wrong' with that disabled person?

Focusing on the impairment by asking what is wrong with the disabled person, is to take an individual or medical model approach to disability.

Disability: What is 'wrong' with society?

Focusing on disability by asking what is wrong with society and why it excludes disabled people, is to take a social model approach to disability.

Therefore, from a social model perspective, impairment is a characteristic feature or attribute within an individual which is long term and may or may not be the result of disease or injury. Disability, on the other hand, is the disadvantage or restriction of activity caused by society which takes little or no account of people who have impairments and thus excludes them from mainstream activity.

Thus, disability, like racism or sexism, is discrimination and social oppression. Impairment belongs to and is owned by the disabled person, disability belongs to and is imposed by society.

For example, the inability to walk is an impairment whereas the inability to get to the first floor of a building because there is no lift is a disability. The inability to move one's body is an impairment but the inability to get out of bed because suitable physical help is not available is a disability.

Disabled people are people with impairments who are disabled by society.

18. Models of Disability

Models are frameworks that help us understand the problems of disability and help us understand the best solutions to disability. There are two main models to consider when looking at disability: the medical/individual model and the social model. DET, the Disabled People's Movement and many others use the social model of disability.

The medical model of disability sees disability as an individual problem, as a personal tragedy; the way that most people in our society, including many disabled people themselves, view disability. It is sometimes called the individual model of disability. The Disabled People's Movement, via the universities, have developed a very different way of looking at disability using the social model of disability. The social model identifies

the problems and solutions of disability as redefined by disabled people, based on our expertise and direct experience. As it implies, disability is redefined as a social (not individual) problem/issue.

Medical Model of Disability

- Views the body as sick or defective. It describes disabled people as ill and in need of treatment.
- Believes the individual disabled person is the problem and sees difficulties experienced as being caused by the individual impairment/condition.
- Views the solution to these problems as cure. The individual is offered therapy, medical aids or operations to enable them to become as ‘normal’ as possible and to fit into society.
- Views the problem of disability as medical and therefore the solutions and expertise rest with the many medical and disability professionals. All areas of a disabled person’s life are specialised and medicalised.
- Is used by governments, local authorities, the NHS, charities, the World Health Authority, etc. as it is the dominant and, for many, highly profitable model of disability.

The medical model says:

- I cannot get involved in the youth club committee because I cannot hear.
- I cannot go to my local school because I use a wheelchair and the school has many steps.
- I cannot find a job because my cerebral palsy stops me getting on the bus to go to work.

The problems with the medical model are:

- Disabled people who do not respond to the treatment may feel the system has failed them and even view it as a personal failure.
- Disabled people are viewed as a burden to society.
- Disabled people are viewed as ‘having something wrong with them’.

- Millions of pounds are spent with little achieved for disabled people.
- By focusing on ‘curing’ the individual, society remains unchanged, the status quo remains.

Social Model of Disability

- Understands disability as a problem created and imposed by society. People with impairments live in a hostile, disabling world designed to suit non-disabled people.
- Recognises that disabled people face systematic discrimination in the way society and its institutions are organised, by the way the environment is constructed and by the attitudes, values and beliefs that develop as a result of the systematic exclusion of disabled people from mainstream society. Disability is a human rights issue.
- Draws attention to the barriers created by society and promotes solutions based on the knowledge that if disability is created, it can be removed without having to change the person or curing the individual’s impairment (in many cases, this is not possible or desirable). Impairment is a reality of life but disability need not be.
- Establishes disability as a form of oppression experienced by people with impairments. This allows the Disabled People’s Movement to make links, exploring the commonalities and differences with other oppressed groups. The solution.
- Lifts the blame from the shoulders of disabled people and places it squarely onto society, thereby liberating and politicising disabled people to challenge society to remove those barriers.
- Comes from disabled people’s own experience and is the basis for all organisations run and controlled by disabled people who promote rights, equality and inclusion for ALL people.

The social model says:

- I cannot get on a bus because it is not accessible.
- I cannot find work because employers will not give me an interview owing to my speech impairment.

- I can't live independently because not enough accessible homes are being built or because my local council will not pay for the help I need.

Some Effects of Disability (from the Social Model)

Disabling attitudes, e.g. fear, pity, repulsion, hatred, superiority, there but for the grace of god, charity cases, incapable, asexual, deviant, live is not worth living, courageous, childlike, marvellous, chip on shoulder, in need of cure, a burden, 'special', victims, 'touched by god', tragic, bitter, abnormal ...

Special/segregated provision in education, housing, employment, transport and many other services means that from an early age, disabled and non-disabled people are separated from each other. Until we are included in society on our own terms and in our own right, discrimination will continue.

Table: Medical Model of Disability vs Social Model of Disability

<i>Medical Model</i>	<i>Social Model</i>
Individual	Collective
Diagnosis	Access
Treatment	Choice
'Special' provision	Independent living
Therapy	Attitudes
Professionals	Information
Research	Action
Care	Rights
Cure	Equality
Ill/Sick	Role models
Rehabilitation	Change
Integration	Inclusion
Normality	Difference
'You must change'	'Society must change'

Disabled people are on average three times more likely to be out of work than non-disabled people and many will have to rely on benefits for their basic income.

Poverty is the greatest disabling factor for the majority of disabled people.

Many disabled people may not be able to access information if their education levels have been limited or if access to materials in a tape, large print braille or computer disc format is not available.

19. The Language of Disability

“I’m embarrassed, I never know what to say ...”

This is commonly said during the language and terminology sessions in DET. Trainers need to understand the importance of language and definitions of disability when faced with responses ranging from defensiveness, to relief, to a misguided belief that if ‘acceptable’ language is used, that will change the world! Words without action for change are meaningless: people may call you a disabled person but if their actions reveal that they treat you like an invalid, then all a change of language has achieved is to gloss over their deeply ingrained disabling beliefs by giving an appearance of acceptance and enlightenment. This maintains discrimination, rather than challenges it.

“Language is always changing ... I can’t keep up!”

Examples of words masking the truth of disability include the use of the word ‘home’ to describe residential institutions or use of the word ‘special’ which, when added to any service concerned with disability becomes synonymous with segregated.

“Does it really matter? It’s all PC nonsense anyway!”

A backlash against political correctness has led to language issues being an annoyance for many and a joke to others. This minimises the powerful

political importance of the words we use to define ourselves and our experience of disability. It is not about being politically correct; it is about having respect for people, valuing people and using the language which they themselves have chosen to define their situation. In the same way that minority ethnic groups, gay people and other oppressed groups have identified the power of language in the promotion of racism, sexism and heterosexism, disabled people understand the way words perpetuate and maintain disablism.

“I know disabled people who call themselves handicapped.”

Disabled people have taken over defining the problem of disability, so too has the Disabled People’s Movement taken over the language used to describe ourselves and our experiences.

“They bite your head off if you say the wrong thing.”

By taking back words that have been imposed upon us, by using new words or by redefining meanings, a new language of disability has been created to reflect this shift in power.

<i>Terms to Avoid</i>	<i>Use Instead</i>
Handicapped	Disabled person
Wheelchair bound	Wheelchair user
Confined to a wheelchair	Wheelchair a mobility aid
Arthritic/Epileptic	Person who has ...
Spastic/MS sufferer	People, not a condition
Invalid (means not valid)	Disabled person
Mentally handicapped	Learning disabled
Mentally ill (nutter/loony)	Mental health system user
The blind/blinkies	Visually impaired person
The deaf (and dumb)	Deaf people
Fun runner/able bodied	Politically unconscious

20. Acceptable Terminology

Acceptable does not mean ‘sounds nicer’.

Acceptable does not mean ‘politically correct’.

Acceptable certainly does not mean words which individualise or medicalise the experience of disability. Acceptable language is those terms which disabled people have chosen themselves in the process of self definition and which are situated within the social model; locating the focus of disability where it belongs, squarely upon society as a whole.

21. No to People with Disabilities

Disabled People vs People with Disabilities: Disabled People's Views

Disabled people and their organisations use the term disabled person because we are disabled by society, not by our impairments. This articulation and terminology is based on the social model of disability; using definitions coined by Disabled People's International in 1981 and subsequently adopted by the British Council of Disabled People (BCODP).

Disabled people refers to ALL disabled people regardless of their specific impairments as it is the commonality of the experience of disability which unifies us as disabled people.

To label yourself a disabled person is (often) a political statement, in exactly the same way that ‘Black’ is a positive assertion of identity in a racist society.

A good parallel is seen when we consider black people. Black people are not ‘people whose skin tone is different from that of the dominant culture’, nor are they people who achieve things despite their ‘blackness’. The term ‘Black’ is a politically motivated identity of a group of people who recognise that: a) they are proud to be the way they are, including skin colours, cultures and languages, and b) they belong to a group of people who are systematically oppressed by the dominant culture which is white, i.e. by racism.

People with Disabilities (oh no!)

Some people use the term people with disabilities because it puts the person first and is more politically correct than handicapped person. From a social model perspective, however, this term is inaccurate, individualistic and it blurs the key distinction between impairment/disability.

Used like this, the term ‘disabilities’ refers to medical conditions, which from a social model perspective, disabled people define as ‘impairments’. People do not have disabilities like attachments compelling them to lead different lives. Society disables people by creating or approving barriers to their inclusion or participation.

What is actually meant when one uses the term ‘people with disabilities’ is ‘people with impairments’.

The distinction is essential for the sake of clarity so that you, we, all know what we are talking about.

22. Disabled People’s Movement

The Disabled People’s Movement in Britain has its roots in the late 1960s and early 1970s when more and more people started openly identifying themselves as disabled people, developing their own ideas of what it meant to be disabled and working together to demand change. Few people realise, however, that disabled people have a rich history of uniting for political and social change which dates back over 100 years. To educate others about our current situation, it is essential to understand the history of disabled people’s self-organisation.

A Few Key Dates

- 1890 The British Deaf Association was formed – the first campaigning group controlled by disabled people.
- 1899 The National League of the Blind was established – a trade union began and was affiliated to the Trades Union Congress in 1902.

- 1920 250 people marched to London in a demonstration organised by the National League of the Blind to force through a law concerning benefits for disabled people.
- 1964 In America, large numbers of disabled ex-servicemen returned from the Vietnam War, unable to return to mainstream life and began to question why. Disability became a civil rights issue in the USA at this point, but not in the UK.
- 1973 A letter to the *Guardian* asking people to write about their experiences of residential care in order to form a network and a pressure group for change.
- 1974 The Union of the Physically Impaired against Segregation was formed and began to define the problem of disability as one which was socially created. Its paper, 'Fundamental Principles of Disability', which documented the distinction between impairment and disability, became the blueprint for collective, campaigning organisations and formulated informal discussions into a formal analysis of the social model of disability.
- 1981 The International Year of Disabled People in 1981 saw the formation of the British Council of Organisations of Disabled People (now the British Council of Disabled People). During the same year, Disabled People's International was formed. This was the official recognition of the Disabled People's Movement.

The first coalition of disabled people was established in Derbyshire – a campaigning organisation controlled by disabled people, based on the social model of disability and committed to the full inclusion of disabled people.

Organisations 'of' Disabled People

Groups run by disabled people for disabled people are often where we first come together to organise and campaign for change. There are however times and places where disabled people come together and nothing changes – if our energies are conveniently sidetracked into basket weaving and bingo, we are not going to build the strong group identity we need

to fight the discrimination that we face daily. Unified groups of disabled people based on a social model vision of breaking down the barriers which create disability are called organisations ‘of’ disabled people, meaning that at least 51% of their management control is in the hands of disabled people.

These groups are mostly local Coalitions or Centres for Independent Living (CILs) working on local issues which have from 51-100% management control by disabled people. Many are run and staffed by a majority of or all disabled people. Organisations ‘of’ disabled people are the foundation of the Disabled People’s Movement.

British Council of Disabled People (BCODP)

The British Council of Disabled People was set up by disabled people in 1981 to promote the full equality and participation of all disabled people within society. As well as having an individual membership scheme, BCODP is an umbrella organisation that represents over 130 organisations ‘of’ at the national level. It is the only national umbrella organisation to be democratically set up by disabled people, to represent their interests at the national level, to be founded upon the social model of disability and, as such, is the heart of the Disabled People’s Movement in the UK. BCODP is part of the world disabled people’s movement through its membership of Disabled Peoples’ International (DPI). Worldwide, our movement encompasses millions of disabled people linked through the struggle for equal rights, a common experience of discrimination and a collective identity.

Organisations ‘for’ Disabled People

The majority of organisations associated with disability are charities and are not part of the Disabled People’s Movement. We call these organisations ‘for’ disabled people because they are not run and controlled by disabled people, the people they claim to be working for.

These organisations are based on a medical model approach to disability, raising money to help us be as normal as possible, using our images to

raise money in our name and maintaining segregation, paternalism and a who knows best approach towards disabled people.

Unlike the Disabled People's Movement, charities divide and rule us into categories based on our impairment groups. They are not accountable to nor representative of disabled people and maintain a charitable rather than rights based approach to disability.

The conflict between organisations of and for disabled people can be neatly summed up in the Disabled People's Movement slogan, 'rights not charity'. This is at the root of why most organisations of disabled people will not work with the Leonard Cheshire Foundation and ask all other organisations and individuals to boycott the foundation.

Role of Charity

In 1351, the government passed a law called the Statute of Labourers which made it illegal for people to give money to beggars capable of working. If those beggars were disabled people, the law did not apply. It was perfectly legal to give money to them as it was assumed disabled people could not work. The unequal treatment of disabled people and their dependence upon charitable handouts have therefore been enshrined in law in this country for over 650 years!

Begging is perhaps a little more sophisticated today, but many would argue that little has changed; with the cutting back of public services, there is an increasing reliance on charitable benevolence to provide very basic services and opportunities. The charity trap places disabled people in a position where they must plead poverty and suffering to receive a share of the spoils that are raised in our name; forced to collude with and maintain the misrepresentative fundraising image of our lives.

It is an issue of power – who has the power to say what we need, how we should be presented to the public, how money raised in our name should be spent? Non-disabled people make these decisions with little reference to those of us whose very existence has given them their jobs and their salaries.

This is further evidenced by, as stated above, the way in which most organisations of disabled people will not work with the Leonard Cheshire Foundation and ask all other organisations and individuals to boycott the foundation. The Leonard Cheshire Foundation is the biggest, richest and most powerful of the organisation 'for' people with disabilities. It clearly understands little and actually exploits disabled people. As an indication of the difference in status: Leonard Cheshire Foundation spends more in a month on public relations than the BCODP has as its annual funding.

23. Issues of Independent Living

Independence

The traditional definition of independence insists that you 'do as much as you can for yourself' and perform 'normal' basic daily tasks before you are allowed to take your place in society. Disabled people, many of whom require assistance and have experienced this tyranny of independence, believe it to be a form of oppression. In keeping with the medical model, it individualises disability, placing the onus on disabled people to cope and adapt in a society designed to meet the needs of non-disabled people. Redefining independence means that it is not about doing everything for yourself, coping on your own or not needing help. Instead, independence is simply about having choices and being in control of what happens to you.

Everyone, disabled or not, relies on other people and is interdependent on other members of society: you can be independent and yet need people to assist you with the practicalities of life.

Independent Living

Independent living is a liberating concept that has its roots in the struggle of the Disabled Peoples Movement from the 1960s onwards. Its purpose is to develop effective alternatives to residential care and traditional individualistic services for disabled people requiring assistance. Independent living is about all people, regardless of their impairment or assistance needs, having choices and control over their lives and an equal

opportunity to participate fully in the economic, social and political life of their community:

“Independent living is the ability to decide and to choose what a person wants, where to live and how, what to do and how to set about doing it. These goals or decisions about a person’s life and the freedom to participate fully in the community have been and will continue to be the essence of independent living. It is also the taking and establishment of self-determination in the total management of a person’s everyday life and affairs.” (d’Aboville, 1991)

This means not only the right to have control over basic daily living tasks – such as when to get up, go to bed, go to the toilet, when and what to eat – but also the right to have personal relationships, be a parent, have equal access to education, training, employment and leisure activities and to participate in the life of the community. Independent living therefore encompasses the full range of human and civil rights.

Centres for Independent/Integrated Living (CILs)

The growth of the Disabled People’s Movement, the development of the philosophy and practical application of independent living and a growing demand by disabled people and their organisations for greater involvement in the development and running of their services, led to the emergence of the first CIL in Derbyshire in 1985. CILs are community based organisations providing a range of services for all disabled people which are controlled and run by disabled people themselves. They are based on the social model of disability and exist to provide flexible and responsive solutions, not dependency creating services.

The National Centre for Independent Living, part of the BCODP, provides a unified voice with influence to promote independent living issues nationally – most notably through the years of campaigning leading up to the passing of the Community Care (Direct Payments) Act 1996.

Seven (7) Needs of Independent Living

While each CIL provides different support and services, it is based upon

the commonly identified 7 basic needs which, if met, will enable true independent living:

1. Information
2. Peer support
3. Housing
4. Aids and equipment
5. Personal assistance
6. Transport
7. Access

In addition to these 7 core needs, some organisations of disabled people have identified the following areas as essential for full and meaningful participation in society:

1. Inclusive education and training
2. An adequate income
3. Equal opportunities for employment
4. Advocacy (towards self-advocacy)
5. Appropriate and accessible health care
6. Direct payments
7. Personal assistance

If, as a society, our environment and services were developed to meet these basic needs, we would be building a society that includes and in which the social causes of disability would be slowly eliminated.

Direct Payments

The unique feature of independent living and direct payments is that they were designed and developed by disabled people who required assistance and wanted 'cash for care' instead of traditional services. As giving cash directly was illegal, for over 20 years, increasing numbers of disabled people received indirect payments to hire the personal assistance they required for living. The effectiveness of these creative schemes and the Independent Living Funds ensured the success of the campaign to legalise direct payments.

The Community Care (Direct Payments) Act 1996 allows social services to offer disabled people a direct cash payment instead of the community care services they had been assessed as needing. Disabled people may use this money to hire the personal assistance they require.

Personal Assistance

Personal assistance makes independent living a reality for many people. Traditionally, the need for personal assistance has been seen as a need for 'care' – a need to be looked after and the 'carer' became the person in charge or in control. The term 'personal assistant' (PA) rather than 'carer' is used to make clear the working relationship wherein the disabled person is the employer of the PA and in control of the assistance provided. Personal assistance means that disabled people exercise maximum control over how services are organised and custom-design the services according to their individual needs, capabilities, life circumstances and aspirations. In particular, personal assistance requires that the disabled person decides:

- who is to work;
- with which tasks;
- at which times;
- where and how.

By opening up access to a full range of life choices, personal assistance can enable disabled people to transform their social identity and reclaim their citizenship. A personal assistant is therefore the means by which a disabled person exercises choice and control and achieves independent living.

24. Disabled People in History

Historically, disabled people have been viewed with a variety of emotions including hatred, ridicule and pity. They have been systematically murdered, persecuted, laughed at and, until fairly recently, excluded almost completely from the economic and social life of the community. The following simplistic look at key phases in history serves to illustrate the creation, development and maintenance of 'disability' through the ages.

From the earliest of times within Christian thinking, the idea of sin and disability has been linked. The implication is that disability is a punishment for our sins or the sins of our fathers. It is only by examining such myths that we can begin to question these values upon which British society was founded and continues to operate.

Throughout the Bible, the emphasis has been towards cure and healing physical and sensory impairments in an attempt to achieve 'wholeness'. This concept has a clear correlation with the familiar, more modern, 'medical model' of disability by implying that impairment is a personal tragedy which necessitates cure or care.

Prior to the industrial revolution, the care of disabled people was on the whole within their own community with their non-disabled peers. Many were forced to beg cap-in-hand on the streets to survive, while others were cared for by their extended families. It was considered shameful to have a disabled person in the family and private care, a luxury of the middle classes, served to enable some to conceal this shame.

The introduction of mass production during the industrial revolution and, with its resulting sale of labour, began the wholesale segregation of disabled people. Society changed from centring around working on the land to working in factories. The machinery and technology which swept the country was designed to be operated by non-disabled people. This created a very clear dividing line between those who could contribute and those who could not. This meant that disabled people became progressively isolated from their peers and, as the extended family gave way to the nuclear family, it became difficult for disabled people to remain in the family environment. The morality of Dickens' times wanted beggars off the streets. Workhouses for the poor, 'asylums' for the 'mad' and institutions (crippages) for disabled people came into being. As these institutions grew in number and size and the staffing in some areas became professionalised, they had to be maintained – thus the growth of the charity business with its non-disabled benefactors and the consequent decline of disabled people into a sub-section of society who required care and pity.

The 19th century saw greater segregation of disabled people. The workforce had to be more physically uniform to perform routine factory operations. As work practices, towns and services were developed and standardised, disabled people became further segregated from society. Increasing mechanisation also meant that more people acquired impairments through accidents at work. Disabled people were rejected, viewed as worthy poor as opposed to work shy and thus given poor law relief. During this time, disabled people became more and more dependent on the medical profession for cures, treatments and benefits.

World War One had a major impact on the image and treatment of disabled people. Many who had served their country in the war came back with impairments, so the idea of 'rehabilitation' was introduced to return them to some sort of 'normality'. It was after World War Two when the first piece of legislation using the term 'disabled people' was used and laws relating to employment, education and welfare services was passed to assist disabled people to be integrated into what had now become an alien environment. Medical and professional dominance, segregated services and charity benevolence were now firmly established.

And the rest, as they say, is history.

Images of Disability

To be a disabled person is to exist within a society where your image and identity are created by beliefs, values, myths, assumptions and stereotypes based on the individualistic medical model of disability reducing our experience to personal tragedy. Our culture is replete with disablist imagery which keeps alive the ancient fears and prejudices surrounding impairment. Where do we get our images of disabled people? Our information about their lives? Where do we as disabled people find role models and images of ourselves in the mainstream media?

Stereotypes

Children grow up associating physical impairment with the malice of Captain Hook and go to bed with images of the crippled witch from

their story book. Film makers use mental illness to portray wickedness and the word disabled becomes synonymous with impotence, hopelessness and social inadequacy. Charity images, children in need, local newspaper campaigns to raise money for little chips, electric wheelchair call us victims, tell the world what we are 'suffering' from all in the name of fundraising. The following examples are eight commonly held media maintained stereotypes of disabled people found in literature, television, newspapers and film:

1. Pitiable and pathetic (i.e. Children in Need/Dickens [Tiny Tim in Christmas Carol])
2. Objects of violence (i.e. Whatever Happened to Baby Jane)
3. Sinister or evil (i.e. Richard III/Freddy Kruger [Nightmare on Elm Street])
4. Super cripple/Triumph over tragedy (i.e. newspaper articles/Heidi/sports coverage)
5. Laughable/Comic (i.e. Mr Magoo/Hear No Evil, See No Evil)
6. Chip on Shoulder (i.e. One Flew over the Cuckoo's Nest/news coverage)
7. Burden/Outcast (i.e. Snow White and the Seven Dwarfs/Beauty and the Beast)
8. Non-sexual/Incapable of having relationships (i.e. Lady Chatterley's Lover/Coronation Street)

Imagine, you turn on the television one evening; the news coverage is of a scientific breakthrough to help people with spinal injury to walk again; there is an advertisement for a major enabling charity asking for your donation to help those less fortunate; the most popular soap has a newly impaired character who deserves all he gets as he was a bad guy, and then the film at 9 pm has a major Hollywood star triumphing over tragedy in his Oscar winning performance as a disabled person.

What messages do we get from such images? Messages about the quality of our lives, our existence, our value as disabled people? Messages which are easy on the eyes and ears as we sit and watch TV but which relate action, prejudice and discrimination. That our lives are not worth living

is a deeply entrenched belief upheld by the media, by society's responses to disability and by our history – a history where disabled people have been segregated into institutions. A history where the Nazi Action T4 Euthanasia Programme killed over 170,000 disabled people designated as unworthy of life. A history where across the world, millions of disabled people have died from unrecorded neglect. The assumption that our lives are not worth living is so deeply held that few people question it as they watch the repeat of this view night after night on TV.

Charity Images

Charities, through their fundraising efforts, create images which prevent the recognition of disabled people as human beings whose lives have value. In competing with each other for the public's cash, charities create a kind of brand awareness of the particular group of disabled people whom they purport to represent. It is advertising which focuses on impairment and turns attention away from the disabling effects of society. The messages are clear: disabled people are their condition, they are imprisoned by their abhorrent minds and bodies and confined by their wheelchairs as they wait for the public's benevolence to cure them or give them a life. Charities and their advertising agencies create the kind of images which they think are going to encourage non-disabled people to give money. They try to create images which evoke pity or feelings of guilt: the act of giving money becomes an insurance policy, an unspoken, thank-god-it's-not-me-or-my-child. Criticisms that charity campaigns demeaned disabled people were met with a change from black and white to colour images and increased consultation by disabled people in the creation of charity images. Is this really progress?

Disability Culture

When the images around you do not reflect your experiences, the only option is to create your own culture. Disabled people have done just that, taking over the words which undermine us and using them to empower us and finding new ways of describing our lives. This is what we are doing when we insist that the word disability describes what society imposes upon us. This is what we are doing when we reclaim the word cripple and

made 'crip' our own, in much the same way as 'queer' has become part of gay and lesbian culture. This is what we are doing when we create our own poetry, stories, theatre, music and humour. The explosion of disability arts in the last 20 years is not about 'positive images' – that is the non-disabled world's attempt to make us normal, believing that it is somehow progressive to pretend that we are like them. No! Our bodies look different, behave differently and we do not have to aspire to be normal to develop ways of representing the reality and value of our lives.

Disability arts is about representing the world from our point of view. It is about using humour to attack the institutions which oppress us. It is about using theatre to rage against the difficulties we face. It is about using photography to celebrate our difference. It is about using words to document our experiences and the richness of our thoughts and lives. It is about songs which leave you 'proud, angry and strong'.

Disability as an Equal Opportunitys Issue

Using the social model of disability, it is clear where discrimination takes place and what measures need to be taken to eradicate it. We must therefore talk about disabled people having equal status and opportunities within society – equal opportunities and access to transport, housing, education, leisure – in fact, everything that makes up the world in which we live. In this way, links can be made with other groups in society who experience oppression as a result of their difference and deviation from what is considered 'normal'.

Experiencing Oppression

Many groups of people within society experience discrimination for reasons ranging from impairment to gender, sexuality, colour, culture, class, age, education, to name just a few. Discrimination occurs when prejudice is put into action and unequal treatment is the result. Anyone and everyone can be discriminated against at some time or other as we act out our prejudices. Certain groups of people, however, experience oppression, i.e. the systematic and institutional discrimination of one group by those who hold the power to deprive people of social and economic privileges.

Sexism, for example, refers to the oppression women experienced from men and disablism is the name of the oppression disabled people experience from non-disabled people. There should be no hierarchy of oppression; one is not worse than another, simply that the response to them varies.

While all forms of oppression are not the same and do not have the same historical roots, there are many links and similarities between how different oppressions are experienced on a day to day basis.

The type of discrimination experienced by disabled people is much more than individual prejudice, being institutionalised within the very fabric of our society. The oppression disabled people experience is detectable when the policies and activities of all types of modern organisation result in inequality between disabled people and non-disabled people. This oppression is rife throughout British society, causing the overwhelming majority of disabled people to experience extreme economic and social hardship every day of their lives.

Multiple Oppression

Too often, the oppression of disabled people is viewed in isolation. It is important, however, to remember that disabled people are women, black people, gay people, from different class backgrounds, different cultures, varying ages, etc. Disabled people may therefore be affected by racism, heterosexism, sexism and other forms of oppression which conspire and compound to ensure they remain on the fringes of society.

25. Civil Rights for Disabled People

History of Disabled People's Campaign for Civil Rights

The history of the campaign for civil rights for disabled people is the history of the Disabled People's Movement and of the development of the social model of disability. The Disabled People's Movement, since the early 1980s, has been focused on the campaign for comprehensive anti-discrimination legislation (ADL) to enable disabled people to participate

fully in the mainstream economic and social life of the community. Disability, as redefined by disabled people through a social approach, was now a rights issue.

The BCODP conducted research and produced ‘Institutional Discrimination against Disabled People: A Case for Legislation’, the first major study to deal with the problems faced by people with impairments within the context of institutional discrimination. It was the first to be conceived, sponsored and written with the full co-operation of disabled people and their organisations. It demonstrated what disabled people knew by experience, that systematic institutional discrimination is a reality of every aspect of their lives. The need for an act to outlaw discrimination and begin to dismantle the disabling barriers experienced by disabled people thus became a collective goal of the Disabled People’s movement, giving a framework for local and national campaigning, lobbying and direct action.

What We Mean by Rights

Human rights, for example reproductive rights, are those rights we have or should have as a human being because we share that right with all human beings, and because human beings need that right in order to exist as individuals and as a species.

Disability is a human rights issue and the Disabled People’s Movement works to campaign for the recognition and protection of our most basic needs and rights to life, existence and humanity. As of October 2000, these rights are directly protected in British law through the Human Rights Act 1998.

Civil rights, for example the rights of access to buildings, are those rights we have as a citizen to participate in public life because all citizens have those rights equally, and these rights are often protected in British law. An example of a law protecting civil rights would be the Disability Discrimination Act 1995 but the inadequacy of this law, other laws and society’s responses to disability means that disabled people do not have legally protected civil rights to equal citizenship and participation.

Entitlements, for example, the right to practical assistance in a person's own home, are those rights which are specific to a group, such as older people, children and disabled people, which other citizens do not have. In this way, an entitlement is a gateway to civil and human rights which otherwise could not be accessed. Many entitlements are laid down in laws, e.g. the Chronically Sick and Disabled Persons Act 1970 or in charters, guidance documents, policies, standards and so on. At a basic level, the failure to acknowledge these basic entitlements is an infringement of a person's civil and human rights.

The Birth of the Disability Discrimination Act 1995 (DDA)

While the first Civil Rights (Disabled Person's) Bill was drafted with the full participation of disabled people and their organisations and introduced by Lord Ashley in 1982, successive governments fought against the need for Anti Discrimination Law (ADL), arguing that there was little evidence of widespread discrimination against disabled people. Based on the dominant individualistic approach to disability, everyday difficulties encountered were linked to a person's impairment and any rare cases of disadvantage were seen as best dealt with by educating to change attitudes, not legislating to ensure rights.

Modelled on the Americans with Disabilities Act 1990, the inclusive and comprehensive Civil Rights Bill had cross party support but the resistance to see disability as a rights issue prevented its enactment. After 17 attempts and considerable political pressure, in November 1995 the Government's Disability Discrimination Bill became an act of law.

The DDA was not the legislation disabled people had been demanding for over a decade but instead was reluctant legislation with hurried consultation. This factor has undoubtedly shaped the act – many definitions are restrictive, justifications for discrimination are broadly defined and businesses with less than 15 employees are exempted. While it is an achievement that disability has been recognised as discrimination and entered the legal arena as a rights based issue, the act can be summed up as one which protects some rights of some people in some situations at some times.

The Disabled People's Movement in general remains unimpressed with the DDA, claiming that it is inadequate, not comprehensive and despite the launch of the Disability Rights Commission in 2000, largely unenforceable. Disabled people continue to campaign, the goal being civil rights legislation which removes the barriers that confront disabled people in mainstream education, the built environment, transport, housing and the health and social support services. In other words, comprehensive ADL that is similar to that in the USA, Canada, New Zealand, parts of Australia and several of our European partners.

Human Rights Act (HRA) 1998

It is a common myth that the introduction of the Human Rights Act 1998 (HRA) will grant us all more 'rights' in the most basic but essential areas of existence. Since October 2000, the HRA has incorporated the European Convention on Human Rights into UK law. This means that the rights we have had protected through the Court of Human Rights in Strasbourg for the last 50 years will now also be protected and enforced through UK courts and tribunals. The act does not create new rights, it simply brings them home and should therefore make them more accessible.

You cannot use the HRA against another individual who may infringe your rights as the act covers only the behaviour of public authorities. These include government departments, local authorities and the police, and it also covers the public functions of organisations such as Railtrack, private schools and charities which provide services on behalf of local authorities.

In order to use the act, a person must be the 'victim' of an unlawful act. An organisation or interest group, e.g. a disability organisation, can bring a representative action on behalf of others if it is able to name all those affected. It can act as a 'friend of the court', arguing on behalf of an unrepresented party.

Where a case is successful, a court may grant any remedy that it considers appropriate, including financial damages, an injunction stopping something from happening or a declaration of rights.

The rights protected by the act are:

- Article 2 Right to Life
- Article 3 Prohibition of Torture
- Article 4 Prohibition of Slavery and Forced Labour
- Article 5 Right to Liberty and Security
- Article 6 Right to a Fair Trial
- Article 7 No Punishment without Law
- Article 8 Right to Respect for Private and Family Life
- Article 9 Freedom of Thought, Conscience and Religion
- Article 10 Freedom of Expression
- Article 11 Freedom of Assembly and Association
- Article 12 Right to Marry
- Article 14 Prohibition of Discrimination
- Article 1 of Protocol 1 Protection of Property
- Article 2 of Protocol 1 Right to Education
- Article 3 of Protocol 1 Right to Free Elections
- Article 1/2 of Protocol 5 Abolition of the Death Penalty

The use to which the HRA will be put by disabled people is still unknown but what is significant is the increasing acknowledgement of rights, bringing human and civil rights into the arena of the media, public authorities and general public. Will it be yet another situation where using the right words will serve to obscure the real issues of discrimination or will the HRA actually make a difference?

Disability Discrimination Act

The DDA is written within the medical model and talks of ‘normal’ values. It specifies physical impairments and mental impairments yet is vague or totally avoids appropriate definitions, leaving large parts of the legislation to interpretation and misunderstanding. Had the social model of disability been used to frame the new legislation, acts of discrimination may have been more clearly defined. Such a definition would have concentrated on the way that an individual is disabled by society, through the identification of barriers to integration, independence and equal opportunities.

By defining disability in the medical context, discrimination in some areas becomes lawful, thus creating even greater confusion for everybody. Perhaps the most positive aspect of this law is the duty upon certain employers and service providers to make reasonable adjustments in relation to policies, practices and the environment which may prevent access to and participation by disabled people. While this is subject to tests of reasonableness, it is nonetheless a recognition of the barriers disabled people experience and acknowledges the duty to remove them.

There are 2 main sections within the act:

Goods and Services

This covers anyone who provides goods or services, i.e. shops, restaurants, cinemas (education and transport are excluded). For example, a restaurant would be expected to make 'reasonable adjustments' if it was 'unreasonably difficult' for a disabled person to make use of its facilities. Discrimination in relation to the letting of premises is also covered under this section.

Employment

This section covers recruitment, training and promotion. For example, if an employer treats a disabled person (for a reason relating to his 'disability') less favourably than someone who does not have a 'disability', the employer may be found to have contravened the DDA, unless he can show the treatment was justified.

Definition

The act defines a disabled person as someone who 'has a physical or mental impairment which has a subsequent and long-term adverse effect on his ability to carry out day-to-day activities'.

Other Areas Covered by the Act

The act also includes disabled people's right not to be discriminated against in the provision of premises. Although transport and education are not specifically covered by the DDA, the government has now drawn up

regulations for new land based transport, the latest date for accessibility being 2017.

The current Special Educational Needs Bill, if passed by Parliament, will extend the DDA to include educational establishments, giving disabled children a stronger but, significantly, no absolute right to mainstream education.

Part Three

For DET Trainers: What Next

Liz Carr and Paul Darke

Whatever brought you to this book, where do you want to go next? As an experienced trainer, perhaps this book has been a useful recap of issues and methods. If you have been on a course and wanted to learn more, hopefully the disability issues and resource elements of this book have helped you develop your understanding of the politics of disability. If you were and are still interested in DET and would like to know more about becoming a trainer, this section is for you!

26. Qualifications for DET Trainers

At the time of writing, there is no standardisation of DET, no register of trainers and no national accredited trainer training course for disabled people. The issue of accreditation, accountability and consistency in DET is currently being discussed within the Disabled People's Movement and in the mean time, non-representative organisations and educational establishments are setting up DET training – the trainer courses that may not be accountable to the movement.

Basically, therefore, there is currently no set pattern to becoming and working as a disability equality trainer. The great thing about this lack

of structure is that rather than adapting to an inaccessible process of qualification, disabled people's organisations are creating their own.

Education has discriminated against many; turning this reality into a qualification means the experience of such oppression and exclusion becomes the major criteria for being a DET trainer.

In a similar way, while mainstream training events and methods have mainly excluded disabled people, isn't this the perfect opportunity to develop methods which are inclusive for all, in line with the creativity of the social model of disability?

27. Essential Skills

Only those who directly experience disability as a form of social oppression will really 'know' the subject matter of DET thoroughly enough to teach about its reality.

As a result of this, it is believed that DET should only be carried out by disabled people equipped with training techniques and a thorough understanding of disabled people's lives from a social model of disability perspective.

Training Techniques

Including facilitation, design and delivery skills, these are useful for anyone involved in training, regardless of the subject matter. It is not enough to know your subject matter; you need the skills, confidence and opportunity to be able to pass this knowledge to other people in a way that impacts them and leads to change. Only training the trainer courses run by organisations of disabled people are likely to combine general training techniques and disability issues. However, local voluntary or disability organisations and your local colleges are likely to organise general courses for trainee trainers. From a day to a few sessions, right up to nationally accredited full-time courses, there are many opportunities to develop traditional training skills.

A Social Model of Disability Perspective

That is, know your subject matter! Being a disabled person gives you first-hand, direct experience of living in a discriminatory society, but being a disabled person is not in itself enough of a qualification – too many disabled people sit in front of a group and spill out their personal history in the name of disability awareness. Disability equality is about all disabled people and the social model of disability. Do you, for example, know about segregated education if you went to mainstream? Or do you know how the Disabled People's Movement developed? You need to know your stuff because that is the knowledge you will be passing on to participants.

Get involved with your local organisation of disabled people, chat with other disabled people and attend any courses on disability issues/personal development type they may be running. Why not while away some hours on the Internet looking at the many disability sites, subscribe to magazines produced by organisations that are part of the Disabled People's Movement. If you have the opportunity, ask to observe other DET trainers to learn ideas and techniques. You can attend a disability equality event for a day or you can complete a course at university in disability issues, but whatever you choose, you need to keep up to date and be aware of current debates.

Beware of who is running the course – with general skills, it is less important who runs the training as long as it is accessible training which meets the outcomes you expect, but with disability related training, it must be training rooted in the social model of disability if you are to become a DET trainer.

28. Training the Trainer Courses

A number of organisations of disabled people run training the trainer courses which cover both of these elements, providing disabled people with the basic knowledge, skills and support to become DET trainers.

Such courses date back to the mid-1980s when disability equality was being developed in line with the growth of the Disabled People's Movement. The London Boroughs Disability Resource Team began to formalise the development of DET, running training the trainer courses, leading to a network of trainers and producing the first DET trainers guide.

Many disabled people have attended this course and the guide have become somewhat of a blueprint for many trainers. Since then, other organisations of disabled people have developed Training the Trainer in Disability Issues Courses and a number of organisations have trainer forums and sub-groups where apart from essential support, issues of ongoing development and local issues can be raised.

Contact your local organisation of disabled people to find out if it has a training group, if it conducts DET training the trainer courses or if it can recommend other local/national resources. To find your nearest organisation, contact the BCODP. Details are in the Resource section.

29. Still Want to be a DET Trainer

You have been on a training the trainer course and now you want to get out there and do your stuff ... but how?

It is important to gain as much and as varied experience as possible, working with people, shadowing, co-training, perhaps having a training mentor to work with you as you gain experience until you are ready to work on our own or be a lead trainer in your own right.

It may be that the organisation you trained with offers further opportunities for development, otherwise, there are a number of training networks and groups which vary in their aims: for example, providing training the trainer courses, hosting a register of trainers, being an 'agent' for work and subcontracting consultants to provide DET on behalf of the network and providing opportunities for less experienced trainers to shadow and co-train.

Training networks tend to be based either on location, e.g. regional networks of DET trainers, or on subject matter, e.g. national networks/registers for those who specialise in education, independent living, etc.

30. Employment Options

For someone starting out as a trainer, being involved with a network or organisation of disabled people is a good way to gain the experience and apprenticeship you need before you are confident enough to move into freelance work. It will often find work for you, provide co-training opportunities and assist you with contracts, invoices and payment issues.

Payment may vary depending on your level of experience, whether shadowing to co-trainer to lead trainer, for example. When you train for an organisation of disabled people, you represent them and train on their behalf and usually a portion of the payment will be ploughed back into the organisation to sustain and develop the training programme.

Many trainers are or become self-employed freelance trainers. This means that they are responsible for all aspects of training – from marketing and obtaining the work, to planning and liaison, designing and delivering the course and organising payment. You are responsible for your finances, including tax and national insurance, on the money you earn.

Often disabled people will freelance yet be involved with different organisations and networks in order to gain experience in different areas and, of course, to gain employment.

31. Marketing Yourself

If and when you go down the road of freelance work, you will be responsible for your own marketing, your own public relations and for selling yourself, your ideas and skills to those looking for training. Even if reputation, word of mouth and informal contacts lead to work

and opportunities, you will still need to somehow communicate such information as what you are offering and what you expect in return.

When you have worked out what you want to tell possible purchasers of your training, you need to decide how you are going to do that. If someone has already approached you for more information, then business cards, compliment slips, headed paper, a CV, a leaflet (etc.) may be things you want to consider. If you are trying to attract business, then apart from a leaflet, standard letter of introduction and promotional website, you may want to put an advertisement in the press, contact local organisations and offer your services or look in the disability press for advertisements asking for training tenders or bids for work.

Work often leads to more work, so always make sure that when you run a course, the participants have some information and details about you so they may contact you in the future.

32. Promotional Material

Creating a Promotional Leaflet

A promotional leaflet about what you provide can be as simple as a side of A4 paper with typed information which should include:

- a brief summary of the type of training you provide;
- personal statement about who you are;
- current and previous clients;
- the core philosophy of your training/company;
- methods used;
- costing and what this includes/excludes;
- minimum and maximum numbers;
- access requirements;
- contact details.

For example:

Dr DET offers a wide selection of disability equality training courses that range from a half day to two days in length. Individual programmes are designed to meet the requirements of specific agencies – including voluntary and statutory organisations, private companies and local authorities. The promotion of the social model of disability, in contrast to the medical one, is a central theme that runs through ALL the Dr's training. The use of videos, group workshops, discussion and the sharing of experience are some of the techniques employed.

Dr DET is a disabled man who has been training in the field of DET for 64 years. His insight into the issues which affect disabled people are a direct result of life experiences. His career to date has included training for Hitler, Leonard Cheshire, Hodge the Bodge, Blunkett's crippage and Duttons fruit and veg shops.

Dr DET's training fees:

One-day course £350

Two-day course £650

Half-day course £175

Consultation 1 hour @ £30

A reduction in training fees for voluntary organisations and organisations of disabled people can be negotiated.

Fees include initial programme consultation and course materials but do not include travelling expenses or accommodation.

A maximum of 15 and a minimum of 8 is the ideal number of participants in any of the courses offered. All training premises must be wheelchair accessible and provide a television, video recorder, flip chart and stand.

For further information, please contact Dr DET at the above address or ring/fax 01666 666 666.

33. Fees

Self-employed trainers working for local authorities usually charge between £250 and £400 per person per day.

There are people who charge much more but especially if you are co-training, this scale is about the right one. In the private sector, the accepted amount paid for training will be higher and at the other end of the scale, voluntary organisations will have little funding available for courses.

For too long disabled people have been asked to give their expertise and skills for nothing and many organisations seem shocked that DET is a job and not an unpaid hobby. It is important therefore not to undersell yourself but to make sure you are paid a decent wage and expenses which reflect that what you are offering and providing is of value and is a professional service. If you undercharge, you will not be valuing the going rate nor your skills and questions of professionalism may be asked when your application, proposal or tender is being considered.

On the other hand, overcharge and you price yourself out of consideration.

Always make sure you are clear concerning fees and expenses.

Usually, the fee covers course design, delivery materials and information packs while expenses cover travel, accommodation and personal assistance costings where relevant.

Some people like to include these as hidden costs in the fee they charge while others include them as expenses.

34. Contracts

Once you have been successful and secured work, you may have a contract between yourself and the organisation purchasing your services. Very few organisations actually provide contracts, but if they do, they will

include more or less everything from your fee to contact details, dates and responsibilities.

The majority of people purchasing your training will be much less formal and give you nothing at all. In this case, it would be up to you to decide if you want to devise a semi-formal agreement for them to sign including costings, named contact person and cancellation arrangements.

If they have not discussed cancellation terms with you, you may wish to put this in your agreement. It is normal practice to ask for a proportion of the payment in the event of their cancellation, depending on how close to the course they cancel. But if the course is rearranged to a mutually convenient date then you could waive the usual terms.

An example of a cancellation agreement may be:

- within 3 weeks of the course: 25% of agreed fee
- within 2 weeks: 50%
- within one week: 75%
- below minimum number of attendees or on the day: 100%

If you work for a network or if you are training on behalf of an organisation, then the contract will be between them and you rather than with the purchasers of the training. Unlike most organisations, DET networks have much more consistent and reliable contractual arrangements.

Do obtain advice from an independent advisor on your employment status if you are just embarking as a trainer. Some organisations that employ you as a freelance trainer may well take off tax and insurance if you do not jump through all the hoops in proving you are self-employed with a schedule D number – each organisation seems to have its own system and way of doing things.

No matter what, you must get yourself organised by keeping all your accounts carefully with proper invoicing of work and receipts for petrol, accommodation, materials, stationery, etc.

An invoice should include the following:

INVOICE	
Name of Client	Invoice No.
Schedule D No.	Invoice Date
Date of course	Details of Invoice
20 May 2001	Disability Equality Training 350.00 124 miles @ .35p 43.40
TOTAL	£393.40
Please make cheques payable to Dr DET and send to the above address.	

* Schedule D No: Tax reference number in the UK

If you are moving more and more into training, it is advisable to use an accountant unless you are personally skilled in this area. If you are training on a very occasional basis, if you have other employment or if you have benefits, it is best to obtain advice on how you should proceed regarding course fees.

None of these situations mean you cannot be a paid trainer, but it is simply a little less straight forward.

Again, if you are working for a network of disabled trainers, it is likely that they will advise you and may be able to assist you through the benefits, traps, etc.

35. Check List and Payment

Pre-Course Check List

Whether or not you have a contract, the following check list is a useful reminder of all the pre-course information and arrangements you may need to agree on:

General

- The client (organisation);
- Address / phone / fax / e-mail;
- Contact person and phone number;
- Course title;
- Date/s of course;
- Time course begins/ends;
- Contract;
- Cancellation agreements;
- Fee and payment arrangements;
- Evaluation form provided by;
- Venue / refreshments / course materials and equipment;
- Venue for the course;
- Client to ensure accessibility of venue;
- Taking issues of accessibility into account;
- Parking /seating / food / drink / other;
- Break times;
- Refreshments provided by;
- Will client photocopy materials (who pays / provided).

Client to Provide

- Flip chart stand and pads, flip chart pens, TV and video player, OHP, other;
- Material in accessible formats: braille, large print, tape, disk;
- Do we need an interpreter, other.

Participation

- Minimum number of participants;
- Maximum number of participants;
- Trainer needs list of participants and their roles by;
- Client will inform trainer of participant access needs by;
- Is the course compulsory or will people choose to attend;
- Is there a mix of job levels;
- Payment.

Do get advice on your employment status, if you are just embarking as a trainer, from an independent advisor.

Some organisations that employ you as a freelance trainer may well take off tax and insurance if you do not jump thru all the hoops in proving you are self employed with a schedule D number – each organisation seems to have it's own system and way of doing things.

Whatever, you must get yourself organised by keeping all your accounts carefully with proper invoicing of work and receipts for petrol, accommodation, materials, stationary etc.

If you are moving more and more into training, it is advisable to use an accountant unless you are personally skilled in this area. If you are training on a very occasional basis, if you have other employment or if you are benefits, you are best getting advice on how you should proceed regarding course fees.

None of these situations mean you cannot be a paid trainer, but it is just a little less straight forward. Again, if you are working for a network of disabled trainers, it is likely that they will advise you and may be able to assist you through the benefits trap.

Part Four

Concepts around Disability and Disabled People

Kenji Kuno

In this section, several models of disability and key concepts and notions around disability and disabled people are explored, namely, participation, social inclusion/exclusion and empowerment. Lately discussed comprehensive framework to analyse well-being of people, capability approach of Dr Amartya Sen, is also discussed as an analytical framework to examine the well-being or freedom of disabled people.

36. Models of Disability

Introduction

Although DET takes the social model of disability as its fundamental framework, it is worth exploring the potential and limitations of the social model and other models of disability. It is difficult to develop a universal definition of disability with simple statements, although various attempts have been made (UN 1999). This is because the perception and understanding of disability are formed through the influence of history, culture and society, and they relate to all aspects of the lives of people (Barnes 1994; Ingstad and Whyte 1995; Barton 1996; Barnes *et al.* 1999, 2002). In addition, terms such as ‘disability’ and ‘handicap’

have been given different meanings in different societies, and in different models of disability (WHO 1980, 2002b; Devlieger 1995, 1999; Nagase 1995; Pfeiffer 2000; Ustun 2001; Hurst 2003). It is important to bear in mind that understanding disability does not simply mean understanding disabled people. A number of other factors must be taken into account in the proper analysis of disability.

Various analytical models of disability have been developed in order to reflect the comprehensiveness and complexity of disability. The potential and limitations of these models to analyse and understand disability were discussed and clarified by comparing a range of models employed by researchers (Altman 2001; Pfeiffer 2001). The comparative analysis of the bipolar models of disability has been central to the discussions of the understanding of the different views on disability, i.e. medical model and social model of disability. Based on such comparison in the 1980s and 1990s, several different views and models which shed light on the diversity of aspects of disability have been developed. Pfeiffer summarised and compared a number of these as follows: medical model, social constructionist version (US), social model version (UK), impairment version, oppressed minority (political) version, independent living version, post-modern (post-structuralism, humanist, experiential, existentialism) version, continuum version, and human variation version. In addition, other models of disability were elaborated on, notably the feminist model of disability and the activity space model of disability, or alliance model of disability (Lloyd 1992; Kopec 1995; Brett 2002). These comparisons were also not universal but are based on cultural background and history of disability and disability movements (Ishikawa and Nagase 1999; Ishikawa and Kuramoto 2002).¹

Although a similar term, 'disability' (or 'disablement' in some cases), is used in these models and views, it is used to mean various aspects of the issues which disabled people face in their lives. In other words, on the one

¹ For instance, 'equalisation view on disability' and 'differentiation view on disability' have been the key bipolar views in the discussion on disability in Japan.

hand it may be important to develop one single definition and apply it in order to clarify the core aspect of disability. On the other hand, it may be more useful to take various models and views of disability together with the understanding of the limitations of each model. This will facilitate a more comprehensive understanding of the issues and problems faced by disabled people.

In this section, the potential and limitations of the following models were considered: 1) medical model of disability, 2) social model of disability, 3) synthesised model of disability, 4) differentia model of disability which includes social model of impairments, culture model of disability, affirmation model of disability, inclusion model of disability, post-modern model of disability, and 5) family model of disability (Table 1).

Models of disability are useful as a tool to understand different aspects of disability (Llewellyn and Hogan 2000). Models and views on disability do not exist in isolation but are developed for a number of reasons: as a critique, to support an approach, or in the development of a new idea or approach. The next section gives a very brief description of the evolution of some of the major models. By clarifying different views on each model of disability and its position to the other models of disability may help to illuminate key notions of each models of disability (Figure 1). By doing so, we are able to obtain a comprehensive view of disability.

Traditionally, disability was understood as fate or punishment in relation to one's beliefs and religion. It was also considered as an unchangeable condition. The medical model of disability dismantled this belief by defining disability as a physical and intellectual condition where change could be brought about by medical or educational interventions. It shifted disability issues from the moral and belief sphere into the realm of the natural sciences. However, a strong emphasis on the physical aspect of disability in the medical model did not reflect the importance of the social aspects of disability. Although in some cases social aspects were considered in terms of 'handicap', all of the causes of disability were aggregated into physical and mental conditions. Another change in perspective arose with the influence of civil rights movements and other social movements

Table 1: Models of Disability

<i>Model</i>	<i>Medical</i>	<i>Social</i>	<i>Synthesised</i>	<i>Differentia</i>					<i>Family</i>
				Social model of impairments	Culture model	Affirmation model	Inclusion model	Post-modern model	
Sub-model	Nagi model, ICIDH	Social constructionist & creationist views	ICF						–
Views on disability	Functional incapability	Discrimination & inequality	Participation Restriction	Personal experience of impairments	Cultural invasion	Negative attitudes	Social exclusion	Socially constructed	Burden
Disabled people	Abnormal	Discriminated	Unequal	Have different experience	Cultural minority	Unique	Everyone is different	Socially constructed	Including family
Focal issues	Functional independence	Social institutions	Functional independence & social structures	Experience	Culture	Attitude	Social barriers	Discourse	Experience
Intervention	Rehabilitation	Social change	Rehabilitation & social change	Dealing with individuals' experience	Positive separation	Affirmation of difference	Social inclusion	Discourse analysis	Intervention to burden

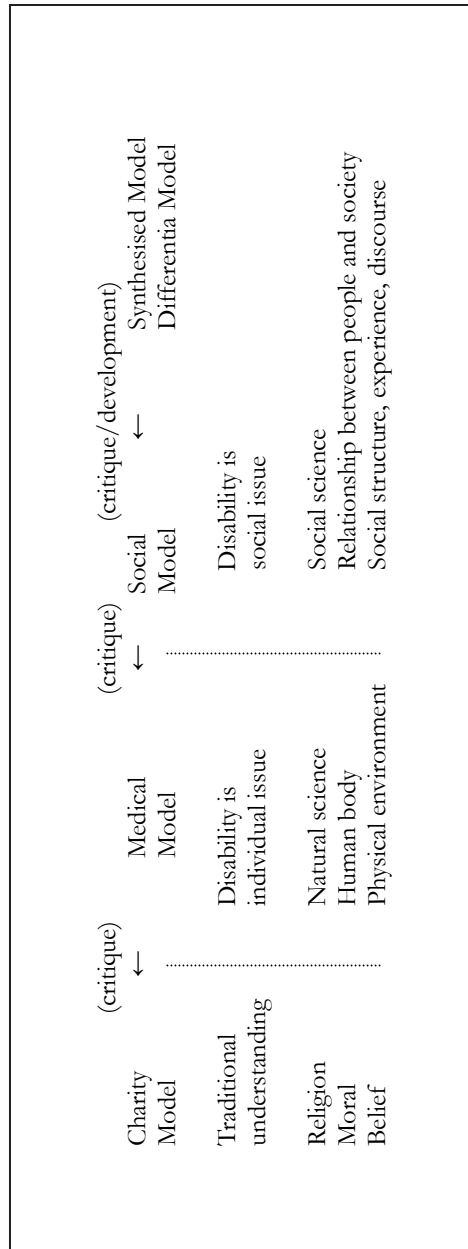


Figure 1: Different Models and Views of Disability

involving segregated people. Disabled people came to believe that disability is not a mere physical or intellectual matter, but oppression and segregation. Institutions and structures of society, which include attitudes of people and legislations, are identified as the causes of disability. This view, developed by disabled people, arose as a critique of the medical model and became known as a social model of disability. By shifting the focus to the interaction of people in society and social institutions, this model transformed the understanding of disability from issues of natural science into social science. However, three key characteristics of this model were criticised and other models were developed based on these criticisms.

The synthesised model of disability, which is the integration of the medical and social model of disability, was developed as a comprehensive model of disability by compensating for the limitations in each model.

The differentia model of disability pointed out the limitations of the social model, which focused only on the aspect of segregation and treated disabled people as a homogeneous group/category of people. Hence, it failed to reflect the various experiences or perceptions of disabled individuals including the experiences of impairments that may not necessarily be an experience of segregation or oppression. All of the above models identify disability only in relation to disabled individuals. However, the family model of disability claimed that disability is not only an issue for disabled people, but family members of disabled people as well. They too experienced disability in different forms and which required recognition, particularly since disability is no longer merely physical and functional issues but incorporates larger social issues as well.

Medical Model of Disability

The medical model can be explained by describing its three dominant characteristics: 1) it views disability as a personal problem and locates disability mainly within the individual; 2) it assumes the causes of the problems directly stem from health conditions, e.g. disease, trauma, functional limitations or psychological losses; and 3) it perceives medical intervention as the primary response to disability (Ustun 1998b: 4).

WHO developed the International Classification of Impairment, Disability, and Handicap (ICIDH) in 1980 as a tool for the classification of the consequences of disease, and defined disability within a linear causal linkage between impairment, disability and handicap (Box 1). This classification of disability is heavily influenced by this model of disability.

Box 1: Definition of Disability in the Medical Model

Impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function.

Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner, or within the range, considered normal for a human being.

Handicap is a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Source: (WHO 1980).

This classification of disability has been widely accepted by rehabilitation professionals, hence by those in Community Based Rehabilitation (CBR). However, it has long been criticised and rejected by disabled people themselves. The major criticism is that it fails to see disability within the social context, and confines disability to physical and mental functions. In the terminology of the ICIDH, the focus is on the impairment of individuals as the ultimate cause of disability and perceives disabled people as passive objects rather than actors (Finkelstein 1992; Oliver 1994, 1996).

Social Model of Disability

The social model of disability was developed by those active in the disability movement who viewed disability as social discrimination and oppression (UPIAS 1975: 14; Finkelstein 1992). The Union of the

Physically Impaired against Segregation (UPIAS), a key organisation of disabled people in the UK, defined disability as follows:

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. ... and disability as the disadvantage or restriction of activity caused by a contemporary social organisation, which takes no or little account of people who have physical impairments, and thus excludes them from participation in the mainstream of social activities (UPIAS 1975: 14).

DPI has opposed the ICIDH since its inception in 1981 by defining disability as follows (Box 2) (Oliver 1994: 63; Hurst 1998: 1).

Box 2: Definition of Disability of DPI

Impairment is the loss or abnormality plus the effect on function.

A ***disability*** is the disadvantage or restriction of activity caused by social factors which take little or no account of people who have impairments and thus exclude them from the mainstream of social activities.

Source: (Finkelstein 1992).

From their own direct experience, disabled people see themselves as disabled by the constraints and negative attitudes imposed on them by a discriminating society – not by their impairments or limitations (Hurst 1998: 1). They do not see the strong causal link between disability and impairment, focusing on what they perceive as the real causes of disabilities, discrimination and prejudice. Oliver (1996: 39) compared these two perceptions of disability and criticised the insufficient understanding of the medical model (Table 2).

In this model, disability is seen wholly and exclusively as a social issue. Hurst (1998: 1-3) states that although there is no ‘normal’ human person, disabled people are seen as different – as deviating from the deemed normal range of what makes up a human being. Therefore, the management of the problem requires social action, and it is the collective

responsibility of society to make the environmental modifications necessary for the full participation of disabled people in all areas of social life. This model assumes not individuals but society should be changed, and this is part of the process of political empowerment of disabled people (Oliver 1996).

Table 2: Comparison of Medical and Social Models of Disability

<i>Medical Model</i>	<i>Social Model</i>
Personal tragedy theory	Social oppression theory
Personal problem	Social problem
Individual treatment	Social action
Medicalisation	Self-help
Professional dominance	Individual and collective responsibility
Expertise	Experience
Adjustment	Affirmation
Individual identity	Collective identity
Prejudice	Discrimination
Attitudes	Behaviour
Care	Rights
Control	Choice
Policy	Politics
Individual adaptation	Social change

Source: (Oliver 1996: 34).

Critiques of the Social Model

There are also several critiques of this model or the dichotomy of models of disability. The first critique is raised by feminists and post-modernists (Devlieger 1999). The deterministic approach of the social model of disability makes individual differences unnoticeable, and denies the recognition of different and unique experiences of disabled individuals (Shakespeare 1994; Barnes 1997; French 1997; Morris 1997; Oliver and

Barnes 1997). Neglecting impairments in the social model of disability, or confining impairments within a biomedical understanding are also criticised, and the need to understand impairments and its experience in the social context is raised (Abberley 1997b).

The second critique is strongly argued by those who consider themselves part of the Deaf culture. They were critical of the assumption within the social model which described the bodily or functional differences or impairments as a negative attribute. Oppression can be justified by seeing physical differences as inferiority in reality (Werner 1992), and it also holds positive attributes as 'uniqueness'. The Deaf community emphasised their own cultural identity, based on the use of a language that is both unique and owned by them (Nagase 1995, 1996b, 1996a; Corker 1998; IDF 1999). Similar changes in perception or self-identification are seen in people with other impairments, through differentiating themselves by giving positive meaning to their body function and structure, not differentiated by others owing to their impairments.

Synthesised Model of Disability

There has been an attempt to synthesise the polarised medical and social models, which presented a thesis-antithesis proposition. It is hoped that a synthesised model would capture the interaction of the various dimensions of disability. The WHO revised the ICIDH and tried to synthesise the two major models into one comprehensive model of disability. In this process, the WHO recognised that the 'pure' medical model, hence ICIDH, could not adequately address disability issues as a whole (Oliver 1996: 36; Ustun 1998a: 4). For this reason, a revised version of ICIDH, i.e. International Classification of Functioning, Disability and Health (ICF), has been developed (Ustun 2001; WHO 2002b).

The ICF has been developed as a scientific tool to reflect the shift in paradigm from the purely medical model to an integrated biopsychosocial model. It aimed at providing various means to map the different dimensions and domains of disabilities (Ustun 1998b: 2; WHO 1998). As it is meant to be a communication tool which would neutralise the

terminology, several terms have been dropped, including ‘handicap’ (WHO 1998). The ICF explains disability in terms of its interactive nature, rather than a linear causal relationship, and defines three dimensions of disability (Box 3, Figure 2).

There are several critiques of this attempt to synthesise the dominant models especially from disabled people’s perspectives (Hurst 1998; Pfeiffer 1998). Major criticism is that despite its attempt to integrate with the Social Model, the underlying principles of medicalisation of disability remain in the synthesised model. This is especially apparent in the conceptualisation of ‘participation’ which is still largely remaining in the domain of activities of daily living. In fact, the concept of participation is less developed compared to other dimensions, even though the concept of participation was the focal point in the revision process (Pfeiffer 2000; Hurst 2003).

Box 3: Definition of Dimensions in ICF

Body functions are the physiological or psychological functions of body systems.

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the performance of a task or action by an individual.

Activity limitations are difficulties an individual may have in the performance of activities.

Participation is an individual’s involvement in life situations in relation to health conditions, body functions and structure, activities and contextual factors.

Participation restrictions are problems an individual may have in the manner or extent of involvement in life situations.

Source: (WHO 2002b).

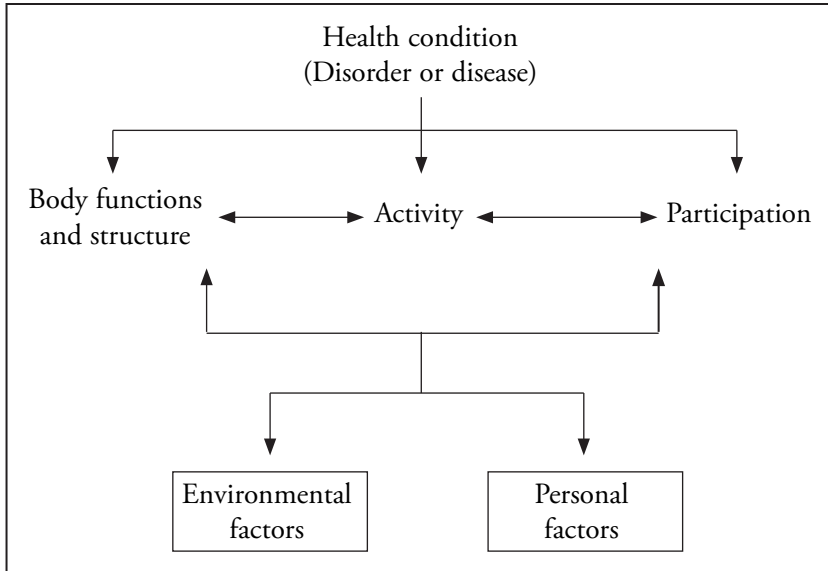


Figure 2: Interactions between the Dimensions of ICF

Source: (WHO 2002b).

Differentia Model of Disability

The term ‘differentia model of disability’ is not used as a specific identifiable model in disability discourse, but was developed by its proponents to categorise several models which shared some common elements. Both the social model and differentia model criticised the medical model’s view of disability. However, the differentia model of disability also points out the limitations of the social model. One limitation is that although it is an important aspect even in the differentia model, the social model focuses solely on the concepts of segregation and oppression. In addition, it treats disabled people as a homogeneous group, oppressed in terms of social relations and fails to reflect the diversity of experiences or perceptions of each individual with impairment. This includes experiences of impairments that may not necessarily be related to segregation or oppression. As noted above, another limitation is that

the social model focuses on the dichotomy between disabled people as oppressed and segregated, and non-disabled people as oppressors, as if the two are distinctive. The differentia model, therefore, emphasises the analysis of the experiences of each individual, interaction of people and discourse.

The above comments summarise the perspective of a number of different models. Different names are used in similar concepts by different researchers which creates a great deal of confusion. Further complicating the issue is the fact that the differences between each model are not clear and some are combined and taken as a single model of disability by some researchers. In order to clarify the key differences between these views making up the differentia model, the sub-models are re-categorised into five models and summarised in the following section.

Social Model of Impairments

The social model of impairments viewed the experience of 'impairments' as a largely negative experience. This is an important factor in understanding the lives and sense of identity of disabled people as well as disability in terms of social oppression. However, this element is neglected in the social model of disability (Houston 2004). This model does not deny the importance of understanding disability in terms of segregation and oppression, but criticises its understanding of it as the main principle in this perspective (Morris 1992). Therefore, disability can be analysed holistically by applying both the principles of the social model of disability and the social model of impairments together. In this way, it can adequately reflect both the discriminative aspect of disability and the experience of impairments, the differences, or being different in society (Abberley 1997a).

The synthesised model and social model of impairments appear similar in terms of giving equal attention to both disability and impairments. However, impairments are viewed mostly from the physical and functional aspect in the synthesised model, but the aspect of its experience is given much focus in the social model of impairments. In contrast, the causal

link between impairments and disability is still strong in the synthesised model as it is inherited from the medical model, while impairments and disabilities are treated relatively separately in the social model of impairments.

However, experiences of impairments, such as pain and functional limitations, are often taken as negative experiences in this model. This view is similar to the position of the medical model, and differs from the viewing impairment as a potentially positive experience as claimed by the affirmation model of disability. Therefore, by analysing impairments using this model, attention is often drawn to the negative experiences of being disabled, thereby re-emphasising the notion that being disabled is a tragedy and an individual matter to be solved by dealing with individuals rather than society. This is criticised as a limitation of the medical model by proponents of the social model of disability.

Culture Model of Disability

The culture model of disability identifies certain groups of people as a cultural minority who share the same culture and experience (such as communicating through the use of sign language), rather than as 'abnormal' individuals as perceived in the medical model, or as oppressed people in the social model (Lane 1995; Kimura 2000). Based on this understanding, their lives and experiences are analysed as a cultural minority in society. Although physical and functional differences, or impairments, are taken as differences and as one of the reasons that a unique culture is developed, they are not considered as a critical factor in distinguishing people. Differences between this minority group and the majority are not based on physical differences but cultural differences. For instance, Andersson, the President of the World Federation of the Deaf (WFD) stated that they are not disabled people but the Deaf. Therefore, using such terms as 'disabled people' to refer to the Deaf people is not appropriate in this model.

I believe that Deaf people in most countries will eventually regard themselves as a linguistic minority instead of a disability group. (Andersson 1994: 10)

In this model, identifying these people as a unique cultural group can be positive, in contrast to a negative identity such as 'abnormal' in the medical model and as 'oppressed' in the social model. While this view of disability has been mainly developed by the Deaf community, its applicability to other groups of disabled people, e.g. people with visual or physical impairments, has been studied and with no consensus as yet.

In this model, differences or heterogeneity is emphasised rather than homogeneity or 'sameness', which is emphasised both in the medical and social models. Therefore, even the concepts of integration or inclusion, which have been accepted as an ideal condition in both the medical and social models, are challenged. Supporters of the culture model maintain that integration may coerce entry of the minority into majority culture, which may lead to cultural invasion of the minority. They propose co-existence as a minority group, with equal opportunity. Therefore, the main issue in this model is coercive integration and cultural invasion by the majority, and its aim is to maintain their own culture.

The Deaf are, however, different from other disability groups. Other organisations call for inclusion and mainstreaming in almost every aspect of life. While not condemning these objectives out of hand, the WFD seeks to keep a cautious distance (IDF 1999: 134).

This model contributes to the development of a positive identity of disabled people, and provides critical awareness relating to the notion of inclusion. However, a major limitation of this model is the incapability to reflect and understand functional difficulty and problems of individuals in daily living, which may have occurred owing to the interaction between impairments and the social conditions. This is due to the notion that neglected physical and functional differences (impairments), as they deny being disabled, i.e. deny having physical and functional difficulties. Hence this view may not be acceptable for disabled people who cannot ignore their physical and functional differences.

Affirmation Model of Disability

The affirmation model of disability views physical and functional differences positively, which had been viewed negatively in both the

medical and social model or ignored in the culture model (French 1997; Gilson and Depoy 2000; Swain and French 2000). Hence, it perceives disabled people as positive beings who have positive and unique differences. This view has made it possible to deal with issues of segregation or oppression without resorting to negative identities, by seeing segregation due to the lack of understanding of the positive uniqueness of disabled individuals.

Although Deaf people dismissed hearing impairments as a minor physical difference, for people with severe disabilities or intellectual disabilities, these profound differences cannot be ignored. In fact, they are one of the main factors of identity. However, by identifying their differences as positive uniqueness, they developed a positive identity of themselves. Statements such as “impairments/disability is my (positive) identity” are based on this notion.

In this model, physical and functional differences are no longer imperfections to be corrected, but beauty or excellence to be embraced. Based on this understanding, this model views the ‘problem’ as lying with society, which does not value these differences positively and discriminates against these people by devaluing their beauty. Although it is similar to the social model in defining social exclusion and discrimination as problems, this model identified disabled people as both talented and oppressed. In contrast, the social model identified disabled people as solely oppressed and this negative self-image paves the way to an understanding of society from a perspective of a dichotomy as either oppressor or oppressed. In contrast to the culture model where heterogeneity is attributed to a group of people, e.g. Deaf people, heterogeneity in this model is attributed to individuals, i.e. this is based on the notion that ‘everyone is different’ and differences must be appreciated, a similar philosophy shared by the next two models. However, this model shares similar limitations as those of the culture model of disability. Practical difficulties due to physical differences can be neutralised because this model views such differences as positive rather than potential limitations or lack of capacity in daily life.

Inclusion Model of Disability

The term ‘inclusion model of disability’ is developed to refer to the concept discussed in the IL Model of disability by Pfeiffer and the social model of disability in the United States by Albrecht (Albrecht 2002; Pfeiffer 2001). The inclusion model of disability was developed using the polytomic view which distinguishes people, i.e. ‘everyone is different’, in contrast to a dichotomous view, ‘disabled people’ and ‘non-disabled people.’ Examples of a dichotomous view include ‘normal – abnormal’ in the medical model, ‘oppressor – oppressed’ in the social model, and ‘majority – minority’ in the culture model.

Although the inclusion model shares a similar polytomic view with the affirmation model and the post-modern model, it is different because it does not necessarily view differences positively. It often views differences as functional limitation. It is also different from the post-modern model because differences are taken as physical differences and not solely as discourse. In contrast to the medical model and synthesised model, which aims to integrate disabled people into society by mainly changing individuals (although it may include some changes in society), this model prioritises changing society. It aims to make society more inclusive; to fit society to every individual, rather than change individuals. Although the social model proposes similar changes in society, its focus is given to institutions based on the perception of disabled people as a homogenous group. In the inclusion model, differences in each individual are the main concern and priority is given to practical interventions to deal with various needs and requirements of individuals to realise equality and inclusion, in addition to institutional interventions. By focusing on the differences of individuals and actual needs resulting from these differences, this model puts disability side by side with other differences, e.g. gender and ethnicity, and gives equal attention to these differences. Disability is no longer a primary distinction but one of several factors to consider individuals’ different needs.

The polytomic view of this model has both potential and limitations. It dismantled the barriers posed by the dichotomous view. Therefore, the

terms 'normal' and 'abnormal' are no longer categories of people, and the term 'normal' person is eliminated. This also promotes cooperation with other people who are also excluded owing to differences and who are denied equal opportunities. However, by eliminating a more familiar social identity such as 'oppressed' or 'excluded', efforts by such a movement or a group demanding particular interventions may be weakened.

Post-Modern Model of Disability

The post-modern model of disability, or post-structuralist model of disability, deconstruction model of disability, was developed based on the philosophy of post-modernism which challenged the notion of objectivity and emphasised discourse (Ingstad and Whyte 1995; Corker and Shakespeare 2002). Therefore, disability is no longer considered as a definitive physical condition but a condition developed and defined by social norms and perceptions of people (Devlieger 1995). For instance, being blind is a condition where a person cannot see, but it is dependent on the social norms and discourse to identify it as a disability (Hughes 1999).

This model points out the importance of understanding people's perceptions and social norms with regard to both disability and disabled people. This model also has a polytomic view and opposes the homogenous view of grouping disabled people. Consequently, this enables the analysis of power relation and inequality within groups of disabled people, e.g. inequality of power between: people with mild and severe impairments; males and females with impairments; rich and poor disabled people. However, the denial of an objective view of disability may raise difficulties in addressing impairments and practical day to day needs owing to physical and functional differences.

In conclusion, the differentia model critically viewed the dichotomous and homogenous understanding of disability and disabled people, and allowed the polytomic view to understand individuals and the different experiences and thoughts among disabled people.

Family Model of Disability

The family model of disability claims that disabled people are not the only ones affected by disability, but family members as well. It argues that although their experience of disability is in a different form, it should be recognised and addressed as disability, since disability is a larger concept than mere physical and functional issues but social issues as well. This expanded view of disability incorporates a wider range of experiences of different but key stakeholders in relation to disability. Although the term 'family model of disability' has not been accepted as an established model of disability, the concept has been discussed in various studies (Kanameda 1999; Ferguson 2001; Brett 2002).

The family model is based on the understanding that each member of the family also experiences different kinds of impact which are caused by the prevailing social norms and the inadequate support disabled people and their families receive from society. If disability is no longer an issue of body function itself, but issues of inequality, then the experiences of family members should be taken as part of disability issues. However, this model is a complementary model, not an alternative to the social model of disability which provides an analytical view of the experiences of disabled individuals. This model expands the scope of primary stakeholders in disability from the exclusive domain of disabled people to incorporate both disabled people and their families by recognising the different types of experience of disability. This model does not imply that family is a unit of analysis of disability, but claims the existence of two (or more) different primary stakeholders who experience different types of problems in relation to disability or as disability. Brett (2002: 832) lamented that parents felt that both their child and themselves were labelled as disabled by society, and consequently found themselves in a situation constrained by societal and environmental boundaries.

This model highlights the notion that each of the disabled person's family members faces various restrictions and burdens owing to the lack of support by society. Their experience of disability overlaps to some extent with the experience of disabled individuals; however it is not necessarily

the same. For instance, disabled individuals may face the need for independence as their problem but independence itself is not an issue for the family. The experience of burden of care and on-going support are more often the disability experience of the family. Since 'disability' in this context is not similar, different disabilities should be distinguished and analysed differently.

As the social model reveals the importance of reflecting the disabled person's own views and experiences in order to understand problems faced by disabled people, it is also important to reflect the family's own views in order to understand their experience of disability. Both views need to be taken in order to achieve a holistic understanding of disability. It is important to understand the differences of experience, perception and interests of these two stakeholders. Parents, for example, are often identified as barriers to independent living of disabled people in the social model perspective. However, the model failed to acknowledge the perceptions and experiences of parents themselves. Incorporating the family model of disability with the social model helps to overcome this limitation.

There are three potential limitations to bear in mind when applying the family model. Firstly, we should not assume the family as a unit of analysis of disability. Disabled individuals and family are distinctive stakeholders of different types of disabilities, although they may share similar problems to some extent. Secondly, we should not assume that all experiences of the family are negative. Most family members have both positive and negative experiences. Their negative experiences, however, are largely due to a lack of social support or prevailing negative social norms. As described above, the third potential limitation is that this model is only capable of providing an understanding of the experience of family members. If other complementary models focusing on the disabled person are not taken into account, then an analysis is largely limited to aspects of care and burden of care.

In this section, an attempt was made to explore various models of disability. There is a common understanding that it is no longer valid to

understand disability solely from the perspective of physical or intellectual functioning, i.e. the medical model of disability. Further, this analysis suggests that the greatest common origin of the meaning of disability can be explained as the outcome of the interaction between a person with impairment and the environmental and societal attitudes (Yeo 2002). Therefore, although the social model of disability also has several limitations, it still provides a fundamental framework to raise awareness disability as social issues.

37. Participation

Since the slogan, 'realisation of full participation and equality of all disabled people' was adopted as the ultimate goal of the International Year of Disabled People by the UN, the concept of participation has been gradually developed into a conceptual framework used to analyse and deepen the understanding of the disability experience. In the field of disability, the concept of participation is often used interchangeably with the concept of equal opportunity and social inclusion. For instance, such interchangeable explanations are found in the two key documents, the World Programme of Action Concerning Disabled Persons (WPA) and the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Standard Rules) (UN 1982, 1993). Adaptation of the concept of participation as an analytical framework was accelerated by the implementation of the new classification of disability of the WHO, i.e. the ICF. It adopted participation and participation restriction as concepts with which to understand social aspects of disability in addition to the traditional concepts of body function and structure and activity limitation. Participation also took central position as an alternative concept and approach in the field of social development. Participatory development and the related concepts of empowerment, decentralisation and participatory approaches have become one of the crucial notions in social development.

In general, definitions of participation refer to the action and rights of individuals to relate with society. Definition of participation for the

International Year of the Disabled Persons (IYDP) gives a relatively comprehensive explanation:

The right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equally to those of other citizens, and have an equal share in improved conditions resulting from socio-economic development. (UN 2000a)

While realisation of both full participation of and equal opportunity for all disabled people was accepted as an overarching goal in the disability field, participation is the dominant concept. This is seen in the fact that participation and recognition of the obstacles to participation are the central platform of the disability movement. The concept is also fundamental in the social model of disability (UPIAS 1975; Barnes 1999; Drake 1999). It is reflected in international policies, such as the UN Convention on the Rights of Disabled Persons, World Programme of Action Concerning Disabled Persons (WPA) and Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (Standard Rules).

‘Full participation’ is defined in the statement issued in the IYDP as mentioned above. In the WPA, ‘full participation’ is adopted as an ultimate goal, prior to prevention and rehabilitation (paragraph 1). These statements acknowledge that full participation within the basic units of society – family, social groups and community – is the essence of the human experience.

As the definition of participation used in the IYDP implies, participation can be viewed from two different perspectives, as a result and as a process. In other words, participation has the potential to be an outcome or result of a disabled person being in an inclusive society. It can also be a means or process of building such a society. While participation is a goal, the importance of the latter perspective on participation is also a central issue in current discussions. The Regional Inter-Agency Committee for Asia and the Pacific (1997) which consists of ten UN agencies and sixteen NGOs including DPI, stated that the participation of disabled people at all levels and in all stages is important, especially in the decision making

process. Their participation as role models as a means of changing prevailing negative images of disabled people was emphasised (Hurst 1998). Such negative attitudes restrict the participation of disabled people as contributors, and exclude them from the decision making processes.

Finkelstein (1998a) argued that it is important for disabled people to participate in the development of an alternative culture leading to a better society. He emphasised that the 'aspirations' of disabled people are the fundamental basis for action to deal with disablements, not the 'needs' that are assessed by rehabilitation professionals. He further states that professionals cannot assess their aspirations because only disabled people themselves are able to identify and realise their own aspirations. Hence, without the participation of disabled people, appropriate actions cannot be developed.

Werner (1994b) highlighted the importance of the participation of disabled people from a more practical point of view, by rating 'being a disabled person' as a positive qualification to be a contributor to a disability related programme such as Community Based Rehabilitation (CBR), not as a negative factor. He identified five reasons for this. By the fact of their being disabled they can: 1) be more sensitive to the needs and feelings of other disabled people, hence have a stronger commitment; 2) give disabled people the opportunity to evaluate their own needs; 3) meet the real needs of disabled people; and most importantly, 4) become a role model for society thereby making CBR an ennoblement or empowerment process; thus 5) it provides a liberating point of view to the disabled people, and it changes rehabilitation professionals whose attitudes are the hardest to change.

In the social development discourse, 'participation' became a critical concept in the 1990s. However, what went under the name of participation took multiple forms, and served different interests, i.e. concepts were highly contested (White and Tiongco 1997: 107). As a consequence, approaches to and outcomes of participatory development

projects are varied, and it is important to clarify the different understandings of participation.

There are several concepts of participation that seem to share a similar feature in that they distinguish the modes of participation by analysing whose interests are served, i.e. those of the implementers or of the people served (Cornwall and Fleming 1995). If the focus is on the implementers, then participation is bound to be discussed in terms of efficiency and sustainability. If the focus is on the people served, then it is more likely that the discourse will be oriented towards empowerment.

Pretty (1995) argued that two overlapping schools of thought and practice of participation have evolved. One views participation as a means of increasing efficiency, i.e. co-opting people to support a project in terms of manpower. The other sees participation as a fundamental right, in which the main aim is to initiate mobilisation for collective action, empowerment and institution building. In reality, participation is more often used for co-option, i.e. people are asked to participate in an operation that may be of no interest to them, in the name of participation. Similarly, White and Tiongco (1997) and Chambers (1997) explained that participation should be an empowerment process but it is often utilised for other goals such as cost effectiveness. Chambers divided it into three categories; a cosmetic label to make whatever appear good; a co-opting practice to reduce costs; and an empowering process which enables local people to do their own analysis to take command, to gain confidence, and to make their own decisions (Chambers 1994). White and Tiongco elaborated it into four types, while Pretty categorised them into seven types (Pretty 1995; White and Tiongco 1997). These three typologies are useful analytical frameworks, and the major types of participation may be classified as in Table 3: just a name; as a means for other ends; and as a goal of empowerment.

Participation and empowerment are two sides of the same coin, and empowerment is seen as the ideal mode of participation. In the next section, the various forms of empowerment will be addressed as has been done with the concept of participation in this section.

Table 3: Typology of Participation

	<i>Chambers</i>	<i>White & Tiongco</i>	<i>Pretty</i>
As a name	Cosmetic label	Nominal	Manipulative
As means for other ends	Co-opting practice	Instrumental Representative	Passive By consultation For material incentives Functional Interactive
As a goal of empowerment	Empowering process	Transformative	Self-mobilisation

Sources: Chambers 1994: 30; Pretty 1995: 1252; White and Tiongco 1997: 106-9.

38. Empowerment

The notion of empowerment was introduced in the 1960s as the “idea that some can act on others to give them power or enable them to realise their own potential” (Nelson and Wright 1997b: 7). It was also described as “the desirable state of affairs in which individuals have choice and control in everyday aspects of their lives: their labour, reproduction, access to resources, etc.” (Hewitt and Smyth 1992: 91). Today, concepts of empowerment are highly contested (White and Tiongco 1997: 107). The definition varies depending on how power is defined. The crucial question that arises from the definitions is who can empower disabled people in the community and how. Three models of power are used to analyse different aspects of empowerment. These are: 1) human development model, 2) political conflict model (which has three different viewpoints), and 3) decentred model. Each is based on different metaphors, and conveys very different ideas about ‘what power is and how it works’.

Human Development Model

This model uses a metaphor of human development and suggests that power can grow infinitely just as human abilities do. In this model,

power is seen as the 'power to'. Rowland (1995: 103; 1997: 110-28) discusses three dimensions of empowerment in this model: personal, close relationships, and collective. The first dimension, personal, refers to the development of the sense of self, confidence and capacity. The second, close relationship, is the development of one's abilities to negotiate and influence decision making. The third, collective, is to work together to achieve a more extensive impact than each could have had alone. In this way, it views the growth of one person as not necessarily negatively affecting another and power can be seen as a 'positive sum' (Nelson and Wright 1997a: 8).

Political Conflict Model

This model consists of three sub-models, but all of them view power as political conflict. Power is viewed as coercive and centred in institutions such as the state; the power relation is seen as a 'zero-sum relation', i.e. if one gains power, the other loses it.

A one-dimensional view of power is based on the pluralist theory, and was developed by Dahl and Polsby as a critique to the elitist theory of power, i.e. there is no single elite in a given society, but power is distributed among different groups (Lukes 1993: 11-5). Power is seen in the actual decision making process in the political arena as observable conflict, and people's interests are seen as policy preferences which are expressed through political participation in the formal political system. Therefore, empowerment is seen as allowing the beneficiaries or their representatives to win in the political arena.

A two-dimensional view of power was developed by Bacharach and Baratz as a critique to the pluralist theory of power, which overestimates the power in the political decision making process (Lukes 1993: 16-20). For instance, equal rights of minorities or environmental issues may not be on the agenda because of restriction, coercion, media control, bribery or threats by 'powerful' people who may lose their advantage by putting these topics on the agenda in the decision making process. Power is seen in both decision making and non-decision making, so conflict may not

be overt but covert, and people's interests are seen as policy preferences or grievances. Persons or groups who create barriers to the public airing of policy conflict, i.e. agenda setting, have power. Empowerment, therefore, may mean to help beneficiaries to raise their issues in the political arena, i.e. put their issues on the agenda in the decision making process.

A three-dimensional view of power is developed by Marxists as a critique to the two-dimensional view of power (Lukes 1993). In contrast to one- and two-dimensional views of power which assume people are aware of their interests, and individuals exercise their power, the three-dimensional view of power conceives that people are unaware of their real interests, so power is seen as the interests of a particular class of people, not of individuals. Power may not be seen as observable conflict but latent conflict, and people can have power without conflict by using their authority or manipulation to shape people's perception or false consciousness of their understanding of reality, i.e. make people accept the present situation as unchangeable. Empowerment, therefore, takes approaches of conscientisation or awareness raising of real interests.

Freire argues that empowerment should be thought of in social class terms, and said, "the question of social class empowerment ... makes empowerment much more than an individual or psychological event. It points to a political process by the dominated classes who seek their own freedom from domination, a long historical process" (Freire and Shor 1987: 108-15). This view of empowerment is taken by numerous grassroots development organisations as a theoretical basis towards the liberation of oppressed people. However, the fundamental question still remains in this view: how the 'real interests' of people can be defined and by whom (Lukes 1993: 26).

Decentred Model

Foucault's view of power is different from the traditional views of power mentioned in the previous two models (Table 4). One fundamental difference is that he does not see power as a zero-sum relation, or win-lose relation. The second difference is that he challenges the notion of

Table 4: Decentred View of Power by Foucault

<i>Foucault's view</i>	<i>Traditional view</i>
(primarily) positive	negative
productive	restrictive
exercised	possessed
omnipresent	localised
set of relation	commodity
from bottom to top	from top to bottom

Source: DuBois 1991: 5.

the sovereignty of a power-centred view of power. Hence, this model is called the decentred view of power (Nelson and Wright 1997b: 9-10). The notion of empowerment is seen as problematic in this model, since power is decentred and omnipresent. Hence, there is no ruling class or fixed distinction between powerful and powerless people, but power flows. This decentred view of power undermines the theoretical basis of emancipatory movements, including Freire, and even suggests that revolution may not challenge power relations.

39. Social Exclusion

The idea of social exclusion first appeared in 'Les Exclus: un francais sur dix' written by Rene Lenoir in 1974. The concept of social exclusion is now extensively used in both social development and disability discourse to describe social disadvantage. However, the concept of social exclusion is still ambiguous, complex, expansive and contested, and can be interpreted and defined in different ways (Silver 1995).

Until recently, a biomedical model focusing largely on impairments of disabled individuals was prevalent, a model which ignored the role of society. Because many disabled people view their exclusion from society as a 'disability', a framework which highlights the interaction of disabled people within society is needed.

The disability movement sees inclusion as an ideal goal while exclusion from society especially in the form of institutionalisation or segregation is seen as detrimental. This goal has been popularised in theory in the development of social models of disability and in practice in the IL movement. As noted earlier, it has been embraced not only by disabled people's organisations, such as DPI and II, but also reflected in two key international policies on disability, WPA and Standard Rules.

In both these policies, while both education and employment are emphasised, exclusion from every aspect of life, including cultural and social life and social security, is recognised as barriers. Another factor in exclusion is human interaction, e.g. attitudes, behaviour or prejudice and discrimination (WPA, paragraph 72). The strongest mode of exclusion recognised in the documents is institutionalisation or confinement of disabled people in institutional care (paragraph 75).

The fundamental advantage of the concept of social exclusion as a framework of analysis, then, is that it focuses on the relationship between disabled individuals and society, or excludes institutions and not merely disabled individuals. Based on this, the social exclusion concept sheds light on social interaction, including attitudinal aspects, and the segregated nature of lives of disabled people. Despite the strengths of the concept, there have been several critiques of its use as a framework of analysis on disability (particularly from the Deaf community) which will be addressed in the next section.

In the social development discourse, the concept of social exclusion rapidly gained recognition after the World Summit of Social Development, and this has led many development agencies to adopt it as a fundamental component in development (De Alcántara 1995; UN 1995; Porter 2000). UNDP also considers social exclusion to be one of the keys to defining and alleviating poverty (UNDP 1997). A speech by the President of the World Bank was centred on issues closely related to inclusive development, apparently in recognition of the importance of socially inclusive development as one of the four key lessons learnt during the last fifty years of experience in development (World Bank 2000: I). The concept of social

exclusion rapidly gained prominence in development, because previous influential development paradigms, namely, trickle down theory, the neo-liberal counterrevolution and the new poverty agenda, could not deal with the question of participation sufficiently (Clert 1999).

Critique of the Concept of Social Exclusion

Two major critiques are raised here, although both are closely related. They are based on the dualistic nature of the concept of social exclusion, i.e. categorising people as 'included' or 'excluded'. This way of understanding disability issues as binary opposites cannot fully explain the complexity of the experiences of disabled people and how these experiences are controlled or regulated by the dominant culture (Corker 1998). The first critique is that the social exclusion concept does not adequately describe situations of unequal inclusion, and more specifically, it does not distinguish between integration and inclusion. For example, integrated classes for the Deaf and hearing children can be viewed as an inclusive goal. However, if there is no appropriate support for the Deaf children, their conditions for learning will not be the same as their hearing peers and perhaps worse off than if they were in a separate educational system. It is not inclusion if there are no equal opportunities and conditions. A second critique is that the concept tends to be 'all or none'; that it completely supports inclusion, and sees exclusion as an absolute negative. On the one hand, positive exclusion can be an empowering process, on the other hand, forced integration can be a disempowering process. The following example shows some of the challenges with the concept of inclusion.

One approach that has been used in education for the past 30 years is integrated education. However, the aim of integrated education is to 'integrate' disabled children into mainstream education based on the dichotomous notion of disabled and non-disabled children. Integrated education often forces the Deaf children to communicate orally and prohibit the use of sign language. This practical application of the idea of integration has been criticised because it maintains its discriminatory nature in its concepts by viewing disabled people as a minority to be integrated by 'normalising' them. In response to these critiques, the

concept of inclusion was developed. In contrast to the dichotomous notion of integration, the concept of inclusion is based on a pluralistic understanding of differences, not a dualistic way. There is no one to be integrated since society is for all. The difference between the concept of integration and inclusion is explained as follows in relation to the Deaf.

Inclusion is: “the process of social and/or educational integration where everyone, whether disabled or not, deaf or hearing, is able to participate, to engage in self expression and to determine collectively norms, codes of behaviour and the necessity for change.” Integration on the other hand is “the process of educating disabled and deaf children alongside non-disabled and non-deaf children in mainstream schools according to hearing and non-disabled norms and codes of behaviour.” The emphasis is therefore on Deaf and disabled children ‘fitting’ into a preconceived and often experientially irrelevant framework (Corker 1998: 146).

The experience of the Deaf people illustrates the futility of seeing exclusion and inclusion in an absolute way. In education, the Deaf people were banned from using sign language until recently in many countries. The rationale was that the use of sign language would hinder the acquisition of the spoken language and hence, obstruct the Deaf people from being integrated in societies. However, this suppression of the sign language threatened both the maintenance of the Deaf culture and the self-esteem of the Deaf individuals. In fact, the Deaf community sees denial of the right to use sign language as a serious problem and the forced integration of Deaf children into the hearing schools as a persecution of the Deaf culture (Nagase 1995: 51; IDF 1999: 133). Segregated or separate approaches are preferred by the Deaf community as an empowerment process, rather than an integrated one. The right to have separate education for the Deaf was acknowledged on an international level in the Salamanca statement that aims to promote inclusive education (UNESCO 1994).

In summary, both integration and inclusion are approaches to preventing exclusion. However, there are different levels of equality among those who are ‘included’. In addition, there are situations where being included is not absolutely positive and where being excluded is not negative and may

even lead to empowerment. Therefore, a social exclusion concept which merely distinguishes the 'excluded' and 'included' may not shed sufficient light on these problems.

Meaning of Social Exclusion and Inclusion

Meanings of social exclusion are embedded in conflicting social science paradigms and political ideologies. Silver distinguishes three paradigms of social exclusion, namely solidarity, specialisation and monopoly paradigms; it could be problematic to have one fixed definition of social exclusion (Appendix II-1). This difficulty, however, provides a theoretical opportunity where multiple meanings of the term serve as a window through which one may view issues from different perspectives (Silver 1995: 60).

Social exclusion is conceptualised in two ways: as a property of individuals and as an attribute of society. In the former, the focus is on the situations of disadvantaged people based on the analysis of socio-economic characteristics of income-poor people. In the latter, focus is placed on institutions and rules, which enable and constrain human interaction (IILS 1996: 11-2; Clert 1999). Social exclusion can also refer to the processes which bring about a lack of citizenship, whether economic, political or social. From this view, social exclusion reduces equality of opportunity and access to resources, including social and material wealth (Rogaly *et al.* 1999: 9-10). It is also important to define social exclusion as a lack of control over one's own life (Ginneken 1998). For instance, many people say that disabled people in developing countries are more included in society than developing countries, since disabled people are more visible than some developed countries. However, this does not mean that they are included in society equally and have power to control their own lives. They may be merely integrated in a society with unequal status.

There are, however, common features of understanding social exclusion: 1) multidimensionality, 2) shedding light on the process and mechanisms, 3) institutions and agencies are seen as actors of exclusion, and 4) attribute

to society, as well as individual (Gore 1995; IILS 1996: 14-7; De Haan 1998a: 11-3; Clert 1999: 180).

Although there are some commonalities, strategies to combat social exclusion vary based on what they are aiming at (Silver 1995: 77). For instance, in the traditional notion of the solidarity approach, exclusion means a deviance or anomie, which both threatens and reinforces social cohesion. Therefore, the inverse of exclusion is integration and the process of attaining it, or insertion. In a Durkheimian sense, this implies assimilation to the dominant culture. This shares the same notion with the traditional understanding of disabled people as abnormal people to be normalised. In this sense, integration does not mean social change but changing of the excluded individuals, or provision of some space in the current society. However, this kind of integration is not seen as an ideal goal in other paradigms. The United Nations Research Institute for Social Development (UNRISD) states that social integration is not how to increase integration per se, but how to promote a kind of integration which favours the creation of a more just and equitable society, i.e. social reform is required (United Nations Research Institute for Social Development 1994). On the other hand, although inclusion is often accepted as absolutely positive without questioning, it can in fact be a negative process as in the case of co-opting or imposition of uniformity. UNRISD summarised three possible results of integration as follows:

- 1) Inclusionary goal: This implies that integration gives equal opportunities and rights for all human beings;
- 2) Negative connotation: Integration becomes a co-option process, i.e. conjuring up the image of an unwanted imposition of uniformity;
- 3) Neither positive nor negative state: It is simply a way of describing the established patterns of human relations in any given society (United Nations Research Institute for Social Development 1994).

The majority of criticisms raised are with regard to the dualistic notion of the social exclusion concept. Although its dualistic features have successfully paid attention to the unequal institutions and relations between the 'included' and the 'excluded', an over-emphasis on the

dualistic structures tends to view the relationship as static or fixed, and misses the fact that people are moving between the 'included' and the 'excluded' in different spheres and time (Jackson 1999; Porter 2000: 77). For instance, an ethnic minority male may be excluded from the mainstream labour market, but within his own community, he may be a leader and 'included' in the local decision making process, whereas female members of the community may be excluded from such processes. In the next section, six limitations and implications of the social exclusion concept are summarised.

The first is the tendency to identify a new group as an excluded group, or stigmatise people as outsiders because of the dualistic notion to distinguish people into two groups (De Haan and Maxwell 1998; Jackson 1999). The second limitation is that this dualistic notion also ignores and undermines an understanding of alternative spaces and counter culture, e.g. feminism or the Deaf culture, in which segregated people have found a space in which they can develop their own understanding of the world and their place within it. This alternative space gives resistance to the mainstream and presents an alternative viewpoint, counter culture or value system to create a more multi-cultural and just society. In other words, inclusive policy could encourage co-opting practices to prevent the birth of counter cultures (Morris 1997; Corker 1998; Jackson 1999). The third point relates to the lack of ability to deal with unequal inclusion. The fourth point is that the social exclusion framework focuses too much on the structural process and it risks missing actual relationships. This undermines the element of negotiation, struggle and resistance to power (Porter 2000: 79). The fifth limitation is the importation of the social exclusion concept from Western social policies. It is based on particular historical processes of industrialisation and formal productive employment, and it may differ from the context in the South (De Haan and Maxwell 1998; Jackson 1999). The last limitation is the lack of measurable indicators (De Haan 1998b). It is always important to ask inclusion in what and on what terms, and to clarify how inclusion and exclusion are defined and by whom, rather than merely to identify who is excluded, since the concept of social exclusion is context dependent (UNRISD 1994; Jackson 1999; Porter 2000).

40. Capability Approach

Introduction

The capability approach provides a comprehensive bird's eye view on the issues and situations surrounding disabled people and their society. It integrates issues around both disability and other social issues which have been dissociated previously.

The capability approach, which was first proposed by Amartya Sen, suggests that the evaluation of personal well-being and social arrangements should be based on what people can be and do (Sen 1992, 1999). It thus shifts the evaluation away from utility, resources and income to the functionings and the capabilities. Functionings refer to people's being and doings, like being healthy, being part of a social network, and being sheltered. Functionings can be specified at the realised level and capabilities at the potential level.

The capability approach advocates that when we conceptualise or evaluate poverty levels, inequality, social policy, efficiency, or development, we should do this in the scope of functionings and capabilities. The approach focuses on people's substantive freedom or real opportunities by looking at their capabilities. Policies should concentrate on expanding people's capabilities.

Sen himself has deliberately formulated the capability approach as a broad framework of thought implying that further specifications and application should always be context dependent. The capability approach has been taken up by scholars in a wide range of fields. It has been taken as one of the important frameworks of thought in the field of social development owing to its potential as an analytical framework to understand the well-being and quality of life (QOL) of people comprehensively, as it is taken as a basis of the UNDP's Human Development Index (HDI) (Anand and Sen; UNDP 1997; Robeyns 2004). Martha Nussbaum has developed her own version of the capability approach to argue for minimal levels of capabilities as a constitutional guarantee. By the same token, the

potential and limitations of this approach have been discussed in the field of disability (Iwasaki 1997b, 1998; Burchardt 2004).

For a long time, issues around disability, e.g. impairments or equality of opportunities, and issues around social development, e.g. poverty, have been analysed within different frameworks and have neither been linked to one another nor taken in a holistic picture, although some attempts were made to develop a framework to reflect both issues in one framework by finding a causal linkage between these two issues (SIDA 1995). However, having identified disability as a cross cutting issue rather than as an isolated issue, the necessity for a comprehensive framework to reflect issues and factors in both dimensions in one large map of analysis has been raised. Therefore, discussions of the potential of the capability approach as a comprehensive framework to analyse disability in the context of social development have gradually emerged especially in recent years (Iwasaki 1997b, 1997a, 1998; Lang and Seddon 1999; Seddon *et al.* 2001; Baylies 2002; Manderson 2002; Welch 2002, 2003, 2004; Kuno and Seddon 2003; Mitra 2003; Nussbaum 2003; Terzi 2003; Bakhshi *et al.* 2004; Demuijnck and Clainche 2004; Hamzetta 2004; Zaidi and Burchardt 2004).

Although Sen refers to the conditions of disability as an example to explain the advantage of the capability approach to grasp the 'practical opportunity' of individuals rather than superficial opportunity, Sen himself had not dealt with the capability approach to disability until recently (Mitra 2003: 14). However, in a recent speech at the World Bank, he referred to the capability approach in reference to disability and concluded that it had potential even for an analysis of disability (Erb and Harriss-White 2001; Sen 2004).

One of the key reasons why the capability approach has been considered as a framework for disability in the above references is that it reflects a wide variety of factors within one framework using the concept of capabilities and functionings. For instance, Mitra stated:

This framework (capability approach) improves our understanding of disability by allowing us to analyse how disability results from the

interaction between the personal characteristics, resources and the environment (physical, social, economic, political) of the individual as well as the person's psychic states (bracket added by author) (Mitra 2003: 2).

Such characteristics are even evaluated as an alternative framework to overcome dualistic discussion in the field of disability (Welch 2002). For instance, the ICF was also one of the comprehensive frameworks which attempted to analyse disability as a biopsychosocial issue, and took the concept of 'participation' and 'participation restriction' as a dimension to analyse social aspects of disability. However, the ICF reflected only disability related factors and do not and cannot reflect non-disability related factors, such as gender, poverty or ethnicity, which are equally important factors to understand the daily lives of disabled people, especially in developing countries (WHO 2002b).

Key Concepts of the Capability Approach

The capability approach is a broad normative framework for the analysis of individuals' well-being, which is primarily a mode of thinking about normative issues, hence – loosely defined – a paradigm (Robeyns 2003: 8). Sen believes that well-being and development should be discussed in terms of people's capabilities to functionings, that is, on their effective opportunities to undertake the actions and activities that they want to engage in, and be who they want to be.

Therefore, the core characteristic of the capability approach is its focus on people's ability to do and to be, that is, based on their capabilities. This contrasts with philosophical approaches that concentrate on people's happiness or desire-fulfilment, or on theoretical and practical approaches that concentrate on income, expenditures, consumption or basic needs fulfilment. Sen argued that in social analysis, the focus should be on what people are able to do and be, on the quality of their life, and on removing obstacles in their lives so that they have more freedom to live the kind of life which they find valuable:

The capability approach to a person's advantage is concerned with evaluating it in terms of his or her actual ability to achieve various

valuable functionings as a part of living. The corresponding approach to social advantage – for aggregative appraisal as well as for the choice of institutions and policy – takes the set of individual capabilities as constituting an indispensable and central part of the relevant informational base of such evaluation (Sen 1993: 30).

The major constituents of the capability approach are functionings and capabilities. Functionings are the ‘beings and doings’ of a person, whereas a person’s capability is “the various combinations of functionings that a person can achieve. Capability is thus a set of vectors of functionings, reflecting the person’s freedom to lead one type of life or another” (Sen 1992).

In Sen’s approach, capability does not constitute the presence of a physical or a mental ability; rather it is understood as practical opportunity. Functioning is the actual achievement of the individual, what he or she actually achieves being or doing. Here, disability can be understood as a capability or functioning deprivation that results from the interaction of (i) an individual’s personal characteristics (e.g. age, impairment) and (ii) his or her basket of available goods (assets and income) and (iii) the environment (social, economic, political and cultural) (Mitra 2003: 4).

A person’s functionings and capability are closely related but distinct.

A functioning is an achievement, whereas a capability is the ability to achieve. Functionings are, in a sense, more directly related to living conditions, since they are different aspects of living conditions. Capabilities, in contrast, are notions of freedom, in the positive sense: what real opportunities you have regarding the life you may lead (Sen 1987: 36).

The difference between functionings and capability can be clarified with an example. Sen’s classical illustration showed the comparison of two persons, one who lived in conditions of famine and another on a hunger strike. Although both persons lacked the functionings of being well-nourished, the freedom they have in avoiding being hungry is crucially distinct. To be able to make this distinction, we need the concept of capability, i.e. freedom, actual opportunity or the functionings that a person *could* have achieved.

Another crucial distinction in the capability approach is the distinction between commodities and functionings. By this distinction, capability can clearly be taken as freedom and actual opportunities to transform commodities to functionings, and the conversion factors are identified: these are *personal factors/characteristics* (e.g. metabolism, physical condition, sex, reading skills, intelligence), and *social and environmental factors/characteristics* (e.g. public policies, social norms, discriminating practices, gender roles, societal hierarchies, climate, infrastructure, institutions, public goods). Take for instance a person with paralysis. Having a wheelchair (commodity), but not knowing how to use it (personal factors), or if the roads are not accessible or community members hold negative attitudes about people with impairments (social and environmental factors), the person's functionings of 'mobility in the community' may not be achieved. Hence, to understand the functionings a person can achieve, it is not enough to know the nature and quantity of the goods a person owns. Additional information is needed about the person and the circumstances in which he lives.

The capability approach does not consider the functionings that a person has achieved as the ultimate normative measure. In principle, it is concerned with his real freedom, that is, with his capability to function, and not with his achieved functioning levels. The functionings of a person are the set of things that he is and does in life, whereas the capability of that person is the alternative combination of functionings that he can achieve and from which he can choose. Capability is thus closely related to the idea of opportunity.

One of the strengths of the capability approach is that it can account for interpersonal variations, i.e. personal or social and environmental factors. This is of central importance to Sen:

Investigations of equality – theoretical as well as practical – that proceed with the assumption of antecedent uniformity (including the presumption that 'all men are created equal') thus miss out on a major aspect of the problem. Human diversity is no secondary complication (to be ignored, or to be introduced 'later on'); it is a fundamental aspect of our interest in equality (Sen 1992: xi).

This is particularly important in the analysis of the well-being of disabled people because their personal factors are varied and it is very much influenced by social and environmental factors (Mitra 2003; Terzi 2003; Welch 2002, 2003, 2004). This aspect is one of the features that make it so relevant in the analysis of the well-being of people in unequal conditions, e.g. women and minorities. Applied in the context of disabled people, it recognised disability as an issue of inequality rather than physical conditions. Sen used the conditions of disabled people as an example to explain the importance of using capability to analyse well-being rather than commodity, because of the variety of influence of the personal, social and environmental conversion factors:

A person who has a disability may have a larger basket of primary goods and yet have less chance to lead a normal life (or to pursue her objectives) than an able-bodied person with a smaller basket of primary goods. Similarly, an older person or a person more prone to illness can be more disadvantaged in a generally accepted sense even with a larger bundle of primary goods (Sen 1999: 74).

Welch (2002) examined the relevance of the capability approach to analyse disability in the context of social development by exploring the similarities of issues in disability, poverty and gender, and concluded that the capability approach can be a single comprehensive framework to examine these issues in one single framework.

When poverty is combined with inequality, regardless if it is based on gender, disability, or socio-economic status, the result is severe failure of capabilities. Interestingly, poor and disabled people as well as women and girls traditionally lack opportunities, resources and support to develop and promote their capabilities. Thus, the application of a capability approach in addressing these areas seems appropriate and a necessary mechanism of intervention for the development of these groups (Welch 2002: 4).

Like other approaches, the capability approach also has limitations and debatable issues. Robeyns summarised them into the following four points: 1) the selection of capabilities, that is, the question of what capabilities constitute a list of relevant capabilities; 2) the dispute around whether

or not the capability approach is too individualistic; 3) the discussion about the critical or conservative nature of the capability approach, and related to that, the treatment of choice and power; and finally, 4) the question whether the capability approach will encourage paternalism and inappropriate policies (Robeyns 2003). These limitations are discussed in relation to the context of disability in the following sections.

Implications of the Capability Approach for Disability

Using the capability approach, the situation of disabled people is pictured as a result of a combination of different factors. These factors include: 1) the nature of impairment and other personal characteristics, e.g. age and gender, 2) the resources available to the individual, and 3) the social and environmental factors (Mitra 2003: 16). The key difference of the capability approach from the ICF is that it reflects other personal characteristics rather than impairments in its analysis. In addition, it considers resources as an important factor resulting in the actual potential and opportunity of disabled people (Mitra 2003). Another key difference is that the capability approach aims at the analysis of the potential of a person to realise a variety of functionings or aspirations rather than actual achievement of the list of functionings which is based on a preset list of expectations to perform by society (Mitra 2003: 20). In other words, the capability approach is based on what individuals value doing and being as opposed to expectations foisted upon them by society. This is the basic assumption in Sen's work and the reason that he is opposed to establishing a 'standard' list of capabilities. This is in contrast to Nussbaum's application of the approach in which she developed such a list of capabilities.

The capability approach has potential to be a comprehensive framework of thought on issues and conditions which relate to disability in the context of social development by its provision of various useful implications. The capability approach makes it possible to understand and analyse issues and factors which have been dealt with differently within two different frameworks in disability and social development. The concepts of functionings and capabilities allow for a comprehensive understanding

of the entire spectrum of life and daily living of people, although some other frameworks also attempt to grasp these issues in a holistic picture in forming causal linkages (SIDA 1995). Most importantly, these issues and factors are not considered independently in the framework, but are transformed into one holistic concept of functionings and capabilities, which explain actual opportunities and freedom in life, hence, the well-being and quality of life of people.

Overall, the capability approach of disability is a holistic approach to disability that accounts for the importance of economic, personal and environmental and social factors in understanding capability deprivation (Mitra 2003: 18).

Disabled people face conditions and issues not only in relation to disability but also other issues just as other members of families and communities do. It may be that issues related directly to their disability may not necessarily be primary challenges for disabled people. Other issues, such as poverty and discrimination due to one's ethnicity or gender, may have a larger impact on that person. Regardless of impairments, people are not free from the culture and the institutions of their society, especially in developing countries where factors such as tribalism, poverty and political restrictions are of greater influence. For example, a scheduled caste disabled person may face greater barriers to finding employment because of his caste than because of the loss of a limb. Therefore, it is important to reflect on these various issues and factors which people face that influences one's own living and life. Although the ICF has been developed as a comprehensive framework to understand disability and the life of disabled people, its comprehensiveness is only within the context of disability and cannot reflect other social and environmental factors and issues in its framework, as WHO itself admitted to as a limitation (Ustun 1998a; Ustun *et al.* 1998). The capability approach, on the other hand, is able to reflect these varieties of factors sufficiently in one framework.

The capability approach provides the basis to identify people polytomically rather than dichotomically by challenging the rhetoric that 'all men are created equal', and acknowledging the diversity of people in relation to their social contexts, which may provide different opportunities. These

differences are reflected as personal factors within the comprehensive framework of capability, without valuing positively nor negatively (Sen 1999). This provides two crucial implications and analytical views to the research on disability. Firstly, it implies that researchers tend to avoid the understanding of life and daily living of disabled people by distinguishing them as disabled people from non-disabled people in general. This implies that researchers need to emphasise the differences of the needs and aspirations of individuals rather than assuming them to be a homogenous group. Secondly, this leads researchers to analyse differences or inequality among disabled people by having a critical view of homogeneity of disabled people but acknowledge differences within disabled people (Terzi 2003).

Based on this potential, eight important implications in the analysis of disability are summarised as in Table 5. Each will be discussed below.

Table 5 Implications of the Capability Approach for the Analysis of Participation of Disabled People and Disability

- Focuses on all factors in three categories, commodity, social and personal factors, rather than on only one of them.
- Does not take factors separately but transforms them into functionings and capabilities to reflect actual opportunities and freedom.
- Takes actual opportunities and equality rather than the formal form of opportunity.
- Analyses potential and freedom rather than achievement or achieved conditions.
- Pays equal attention to the aspect of agency as well as well-being.
- Reflects the diversity of the aspirations of individuals and society rather than applying a preset list for analysis.
- Reflects different forms of disabilities.
- Identifies various areas of and strategies for intervention in practice.

Focuses on all factors in three categories, commodity, social and personal factors, rather than on only one of them

The capability approach highlights the importance of understanding the well-being of people by reflecting on three factors: personal, social and environmental factors. It also provides a framework which reflects all factors in one comprehensive picture. One's life and well-being is influenced by factors in these three categories and it is particularly important to analyse the participation of disabled people with regard to their personal and social conditions.

Does not take factors separately but transforms them into functionings and capabilities to reflect actual opportunities and freedom

The capability approach reflects actual opportunities rather than traditional or institutional opportunities. Capabilities reflect actual potential or freedom to be or to do by transforming various factors into capability. For instance, even if equal opportunity for the education of disabled children is assured in legislation, some disabled children may not be able to attend school owing to poverty or uncontrolled epilepsy or family member's attitude. It may not be possible to understand actual opportunity for education owing to these factors if it is assessed and analysed solely by institutions or legislation. The capability approach ensures that a variety of factors are considered and it provides a framework through the introduction of the concept of capabilities.

Takes actual opportunity and equality rather than the formal form of opportunity

The capability approach emphasises the understanding of actual opportunities directly, rather than assuming it indirectly by analysing means. Take for example, formal opportunities to protect access to education through the implementation of a barrier-free environment or legislation to protect the rights to education of disabled children. Despite this, some children may not have actual opportunity for education owing to other factors; individual or social, which influence the realisation of such functionings and capabilities such as poverty or distance to school. This emphasis on the analysis of actual opportunities directly implies the

importance of researching the detailed background of one's life in relation to society rather than assuming it indirectly by focusing solely on an analysis of social institutions.

Analyses potential and freedom rather than achievement or achieved condition

The capability approach implies the importance of the analysis of well-being and QOL by freedom or actual opportunities to realise various functionings rather than actual achievement of such functionings through the use of the concept of capability. This is very important for the analysis of participation of disabled people as it allows for the use of potential and possibilities in addition to actual achieved condition to analyse participation as equal opportunity. Opportunity for education or employment, for example, should not be analysed only if disabled people are currently attending schools or are employed, but also if they wished in particular conditions. The meaning of the situation where a disabled child is attending a CBR centre instead of school in a village can vary if attention is paid to actual opportunities, that is, whether that child has actual opportunities to attend school or not, and whether the decision is of that child and family or school authorities.

Pays equal attention to the aspect of agency as well as well-being

One of the key features of the capability approach is that it reflects both well-being and agency, which is personal commitment or action for good that is not beneficial to one's well-being, separately in a single framework without squeezing them into one (Sen 1992). Participation of disabled people as implementers or decision makers in the process of CBR, for example, may not necessarily improve their well-being but can contribute to the realisation of a better society.

Sen observed that it was his aim to explore a moral approach that sees persons from two different perspectives, well-being and agency although these are thoroughly interdependent. Both well-being aspect and agency have their own relevance in the assessment of status and actions and these two aspects are the central concepts in his capability approach (Sen 1992: 57; Jensen: 9).

Reflects diversity of aspirations of individuals and society rather than applies preset list for analysis

Although this aspect of the capability approach is often criticised as a limitation by various researchers, it is important that it reflects the diversity of individuals and society. In contrast to Nussbaum, Sen does not propose a definite list of capabilities. He reasons that such an attempt may tremendously over-specify human nature, and state the importance to preserve this ambiguity or flexibility to understand general capabilities which may vary depending on one's own aspiration and the conditions of society (Yamamori 2003: 18). This, then, implies that the significance of understanding an individual's aspirations in relation to the social conditions can be highlighted using qualitative methodologies. These methods emphasise the understanding of the lives of individuals in relation to their social context in contrast to quantitative approaches that apply a standardised index to analyse the capabilities of individuals. The strength of the capability approach is to make the selection of relevant evaluative dimensions an explicit social choice exercise, while the medical model of disability has a fixed and limited set of evaluative criteria (Mitra 2003: 23).

Reflects different forms of disability

As will be discussed in the family model of disability, disability issues may influence different people in different ways regardless of whether they are with or without impairments. The capability approach reflects these different forms of disabilities accordingly and transforms them into functionings to understand one's condition holistically.² In the case of a disabled person, his impairments may be taken as a personal factor, but for his family, their physical or financial burden may be taken as an environmental factor and both are transformed into functionings and capabilities.

² For instance, anxiety is listed as one of the major issues for families of disabled people. This can be analysed as a functioning of 'having a life without fear and anxiety', and factors which raise this anxiety can be represented in three categories, e.g. financial limitation (commodity), lack of support in community (environment/social), or too old to look after a disabled child (personal), and transformed into capabilities.

Identifies various areas of and strategies for intervention in practice

This feature of capability approach has both potential and limitations. The capability approach understands lives of people through the concept of capability, which is formed from conversion factors, i.e. personal, social and environmental factors. As long as functionings and capability is improved, areas of intervention are not restricted. This leads to various areas of intervention in practice according to the conditions of society and capacity of intervening agencies. Taking the functionings of 'having education' of a disabled child who uses a wheelchair as an example; it is possible to see that the child's capability could be restricted for a number of reasons: if her family has enough money to send her to school (commodity), if she can push her wheelchair to local school (personal factor), or if the school is barrier free to accept her in her wheelchair. This analysis leads researchers to identify areas of intervention and means of intervention to be decided according to possibilities, appropriateness and preferences of the child and her family.

Consideration Points of the Capability Approach

As in all conceptual models, caution must be taken in the application of the capability approach. Various researchers have pointed out ambiguities and limitations of the capability approach (Cohen 1993; Qizilbash 2001). Five limitations are summarised in Table 6. But before considering these, it is important to address differences in terminology. These differences are not really a limitation of the conceptual framework, but the particular use of the terms in the framework may mislead researchers. A major limitation is the use of the term 'disability' in Sen's work on the capability approach. Sen often used the term 'handicap' or 'disability' to explain a body function and structure or impairment as defined in the ICF or ICIDH. This refers to the physical and mental conditions, rather than disability as an outcome of the interaction between the individual and society, which is in fact one of the capabilities of Sen's conceptual framework. The different use of the terms may create confusion and mislead researchers into incorrectly understanding disability as a condition of physical and mental ability only, not as an outcome of the interaction of individuals and society (Mitra 2003: 14). Similarly, the term 'capability' is given a unique meaning

Table 6: Factors to be Considered When Applying the Capability Approach as a Framework for Analysis of the Lives of Disabled People

- Capability approach may not provide a framework to analyse the causes of each factor.
- Capability approach allows various areas and modes of intervention.
- Capability approach may not clarify actors of intervention.
- Difficulty in dealing with choices of people who have problems with decision making.
- List of capabilities/functionings is not fixed.

within the concept of the capability approach which is different from the general use of its term as individual potential without referring to external conditions. Capability as a concept of the capability approach means the overall outcome of three conversion factors, i.e. individual, social and environmental factors. Those who do not clearly understand this use of the term ‘capability’ may be misled into understanding the capability approach merely as a framework to analyse the aspect of individual ability without reflecting other social and environmental factors.

Although this framework provides a tool to analyse causes of condition of functionings and capabilities by reflecting the environmental, social and personal factors, it may not provide an analytical framework to identify causes of the condition of each factor. In order to overcome this limitation in this study, models of disability and a more detailed framework for analysis of participation will be used to compliment the analysis using the capability approach. For instance, the capability approach provides a framework that may reveal personal, social and environmental factors that restrict a disabled child from attending school. However, it does not provide a framework for the analysis of why these factors are posing such restrictions. While the cause may be that the school is not barrier-free, such causes are more appropriately analysed by the social model of disability.

Related to the first limitation explained above, there is potential to deal with only interventions in personal domain such as impairment instead of

finding the root and fundamental causes of the restriction of capabilities. This flexibility or capacity to accept diverse intervention may suggest interventions which may not be ideal for disabled people but may be preferred by those who provide intervention, e.g. family, doctors or teachers. This is certainly true in the case where rehabilitative interventions have been embraced to address disability based on the medical model regardless of choice of disabled individuals. Researchers need to bear in mind that functionings and capabilities arise from factors in all three categories; social, environmental and personal, and they need to seek the causes of restrictions in all three rather than in a single category.

Sen explained that intervention in the realm of capabilities is development, and it can be explained as empowerment (Bhatia 2001). However, Sen does not imply who should take this role, e.g. government, civil society or people themselves, and how they should do so within this framework. In other words, actors of empowerment are not clearly defined. Although Sen criticised paternalistic interventions and emphasised the idea that people themselves should be change agents, he also notes the positive role of the government and development agencies as interventionists in conditions such as poverty (Qizilbash 1996; Sen 2000). On the other hand, the participation of primary stakeholders, i.e. disabled people, is one of the main concerns in the field of disability, and this aspect of policy may not be sufficiently emphasised in this framework.

Cohen commented that the capability approach brings conceptual confusion in evaluation by emphasising freedom in its framework (Cohen 1993). Cohen used the example that babies do not choose to eat and drink for survival by their own will. Iwasaki also pointed out difficulties in reflecting the well-being of people with problems in decision making, e.g. people with learning disabilities or psychiatric problems, because well-being is analysed as freedom rather than achievement in the capability approach (Iwasaki 1997a). Sen himself agreed that it might be better to analyse well-being as achievement rather than as freedom in some of these cases (Sen 2000). Analysing well-being as freedom instead of achievement is the central feature of the capability approach, and denying the application of this notion to people with certain conditions implies

a fundamental limitation of this framework when applied to disabled people. However, as Iwasaki suggested, the ability of decision making varies regardless of disability or age in relation to social and environmental matters with regard to making decisions, and such ability in decision making can be reflected as a personal factor of functionings of 'making decision' (Iwasaki 1997b).

Although it is positive potential to reflect a individual's aspiration into analysis, not using a predetermined list can also be a limitation of the capability approach to some extent as Nussbaum pointed out (Nussbaum and Sen 1993). For instance, it makes it difficult to compare capabilities if there is no universal set of capabilities. However, such comparison itself is criticised as incapable of reflecting individual aspirations. Qualitative inquiries which animate the life of people and comparing it within a detailed context may provide more useful insights (Albrecht and Devlieger 1999).

Conclusion

Similar to other frameworks of thought, the capability approach has several limitations. Despite these limitations, the capability approach provides a comprehensive framework to analyse disability through its integral view of people's lives and QOL. The capability approach provides a useful framework of thought on disability with respect to two features. Firstly, it provides an integral and comprehensive analytical view of issues and conditions which have been analysed in separate frameworks and paradigms in the fields of social development and disability, by introducing functionings and capabilities as integral concepts which reflect and transform differentiated issues in these two different fields into one synthesised concept of capabilities. Secondly, it values both well-being and agency as two distinctive concepts but within one comprehensive view. By these features and potential, participation of disabled people can be analysed not only in relation to the condition of disability but also in relation to the diversity of depth of their lives. This analysis is done by reflecting other dimensions which affect disabled people, such as gender or poverty, and the analysis centres not only in the aspects of people's well-being but also as change agents.

Postscript

The original writing for the book was as part of a UK National Lottery funded project, for which we as the writers were very grateful. But no book is worth anything if it is merely read. It needs to be disseminated and lived. Equality is not something offered to someone else who is seen as less equal than you are: equality is the absolute intrinsic right of all people (disabled and non-disabled; black and white; male and female; adult and child; and everybody else). For too long disabled people have waited to be given equality – now is the time to take it. May this book give disabled people and non-disabled people the tools to take equality to a new level.

All that is offered in the book is written on the basis that society is not naturally inequitable. People, and their societies, are naturally just. It is only in the last few hundred years that societies have been distorted by capitalism, religion, industrialisation and, more recently, the media (in all its forms). As such, this book is an optimists guide to achieving equality and – logically following on from that optimism – it is mainly optimists who will use and benefit from it. Never be afraid to see the optimist in even the most cynical pessimist (the spark of hope – like love and democracy – is waiting to be lit in the darkest of corners of the blackest room in the gloomiest neighbourhood). This book will hopefully be your map, your guide, through the shadows of despair right through to the hope of a better future.

In reading this book, we hope that you have not been ‘put off’ the drive to equality nor has it made you feel that its instructions must be adhered to

by the letter. Each individual, group or organisation may come to equality by a different path and they may need to take a slightly different route to go as far down that road as possible. This book should be used as a starting point for your own creativity, wit and approach as long as you stick to its principles. Do not be afraid to take what it suggests and take it further or tone it down: feel free to make your advocacy for equality more challenging or less challenging depending upon the people you are working towards equality with. Do not be afraid to tailor the training to suit your needs and those of those you may be training. You can, and should, use your strengths and the strengths and awareness of those you train to achieve as much awareness and equality as is possible today. Do not be put off by failure: equality is a right but one which few are ready for today: but they will be tomorrow if you did today right.

Paul Darke

References

- Abberley, P. (1997a). Disabled People and 'Normality'. *Disabling Barriers: Enabling Environments*. J. Swain, V. Finkelstein, S. French and M. Oliver. London, Sage Publication.
- _____ (1997b). The Limits of Classical Social Theory in the Analysis and Transformation of Disablement: (can this really be the end; to be stuck Inside of Mobile with the Memphis blues again?). *Disability Studies: Past, Present and Future*. L. Barton and M. Oliver. Leeds, The Disability Press.
- Albrecht, G. L. (2002). American Pragmatism, Sociology and the Development of Disability Studies. *Disability Studies Today*. C. Barnes, M. Oliver and L. Barton. Cambridge, Polity Press in association with Blackwell Publishers.
- Albrecht, G. L. and P. J. Devlieger (1999). "The Disability Paradox: High Quality of Life against All Odds." *Social Science and Medicine* 48: 977-88.
- Altman, B. (2001). Disability Definitions, Models, Classification Schemes, and Applications. *Handbook of Disability Studies*. G. Albrecht, K. Seelman and M. Bury. Thousand Oaks, California, Sage Publications.
- Anand, S. and A. Sen (1994). Human Development Index: Methodology and Measurement. http://hdr.undp.org/docs/publications/ocational_papers/oc12.pdf (accessed on 22 December 2004).
- Andersson, J. (1994). Deaf People as a Linguistic Minority. *Bilingualism in Deaf Education*. I. Ahlgren and K. Huytensam. Hamburg, Signum: 9-13.
- Bakhshi, P., et al. (2004). *Enhancing Security and Social Sustainability*, Barnes, C. (1994). Images of Disability. *On Equal Terms: Working with Disabled People*. S. French. Oxford, Butterworth-Heinemann.
- _____ (1997). A Legacy of Oppression: A History of Disability in Western Culture. *Disability Studies: Past, Present and Future*. L. Barton and M. Oliver. Leeds, The Disability Press.
- _____ (1999). "Disability Studies: New or Not So New Directions?" *Disability & Society* 14(4): 577-80.

- Barnes, C. and G. Mercer (1995). Disability: Emancipation, Community Participation and Disabled People. *Community Empowerment: A Reader in Participation and Development*. G. Craig and M. Mayo. London, Zed Books.
- _____ (1997). *Doing Disability Research*. Leeds, The Disability Press.
- Barnes, C., et al. (1999). *Exploring Disability: A Sociological Introduction*. Cambridge, Polity Press.
- _____ (2002). *Disability Studies Today*. Cambridge, UK, Polity Press in association with Blackwell Publishers.
- Barton, L. (1996). *Disability and Society: Emerging Issues and Insights*. London, Longman.
- Baylies, C. (2002). "Disability and the Notion of Human Development: Questions of Rights and Capabilities." *Disability & Society* 17(7): 725-39.
- Bhatia, M. (2001). Operationalising Empowerment in Bank Operations: The Measurement Challenge.
- Brett, J. (2002). "The Experience of Disability from the Perspective of Parents of Children with Profound Impairment: Is It Time for an Alternative Model of Disability?" *Disability & Society* 17(7): 825-43.
- Burchardt, T. (2004). "Capabilities and Disability: The Capabilities Framework and the Social Model of Disability." *Disability & Society* 19(7): 735-51.
- Chambers, R. (1994). *Challenging the Professions: Frontiers for Rural Development*. London, Intermediate Technology Publications Ltd.
- _____ (1997). *Whose Reality Count: Putting the First Last*. London, Intermediate Technology Publication.
- Chambers, R. and G. R. Conway (1992). "Sustainable Rural Livelihoods: Practical Concepts for the 21st Century." *IDS Discussion Paper No. 296*.
- Clert, C. (1999). "Evaluating the Concept of Social Exclusion in Development Discourse." *The European Journal of Development Research* 11(2): 176-99.
- Cohen, G. A. (1993). Equality of What? On Welfare, Goods and Capability. *The Quality of Life*. C. Nussbaum Martha and K. Sen Amartya. New Delhi, Oxford University Press.
- Coleridge, P. (1993). *Disability, Liberation, and Development*. Oxford, Oxfam.
- _____ (2000). Disability and Culture. *Asia Pacific Disability Rehabilitation Journal, Selected Readings in Community Based Rehabilitation: Series 1 CBR in Transition*. M. Thomas and M. J. Thomas.
- Corker, M. (1998). *Deaf and Disabled, or Deafness Disabled?* Buckingham, Open University Press.
- Corker, M. and T. Shakespeare (2002). *Disability/Postmodernity: Embodying Disability Theory*. London, Continuum.

- Cornwall, A. and S. Fleming (1995). "Context and Complexity: Anthropological Reflections on PRA." *PLA Notes* (24): 8-12.
- Curry, R. (2003). Barriers to Practice for Indigenous Remote Area Community Based Health and Social Service Workers. Discussion paper, CBR Forum SARRAH, Brisbane.
- d' Aboville, E (1991) "Social Work in an organisation of disabled people" in Oliver, M (ed.), *Social Work: Disabled People and Disabling Environments* London, Jessica Kingsley.
- Davis, L. (2001). Identity Politics, Disability, and Culture. *Handbook of Disability Studies*. G. Albrecht, K. Seelman and M. Bury. Thousand Oaks, California, Sage Publications.
- De Alcántara, C. H. (1995). "Social Integration: Approaches and Issues." *Development in Practice* 5(1): 61-3.
- De Haan, A. (1998a). Social Exclusion in Policy and Research: Operationalising the Concept. *Social Exclusion: An ILO Perspective*. J. Figueiredo and A. d. Haan. Geneva, ILO.
- _____ (1998b). "Social Exclusion: An Alternative Concept for the Study of Deprivation?" *IDS Bulletin* 29(1): 10-9.
- De Haan, A. and S. Maxwell (1998). "Poverty and Social Exclusion in North and South." *IDS Bulletin* 29(1): 1-9.
- Demuijnck, G. and C. L. Clainche (2004). An Exploration of Our Widely Shared Intuitions about Responsibility and Circumstances Focused on Disability. Paper presented at the 4th International Conference on the Capability Approach: Enhancing Human Security, held at University of Pavia, Italy on 5-7 September.
- Devlieger, P. (1995). Why Disabled? The Cultural Understanding of Physical Disability in an African Society. *Disability and Culture*. B. Ingstad and S. R. Whyte. London, University of California Press.
- _____ (1999). "From Handicap to Disability: Language Use and Cultural Meaning in the United States." *Disability and Rehabilitation* 21(7): 346-54.
- Drake, R. F. (1999). *Understanding Disability Policies*. Hong Kong, Macmillan.
- DuBois, M. (1991). "The Governance of the Third World: A Foucaudian Perspective on Power Relations in Development." *Alternatives* 16: 1-30.
- Ellis, F. (2000). *Rural Livelihoods and Diversity in Developing Countries*. Oxford, Oxford University Press.
- Erb, S. and B. Harriss-White (2001). Disability and Incapacity. *Reforms and Development: Essays on Long Term Village Change and Recent Development Policy in South India*. B. Harriss-White and S. Janakarajan. <http://www.livelihoodoptions.info/frames.htm> (accessed on 24 March 2004).

- Ferguson, P. (2001). Mapping the Family: Disability Studies and the Exploration of Parental Response to Disability. *Handbook of Disability Studies*. G. Albrecht, K. Seelman and M. Bury. Thousand Oaks, California, Sage Publications.
- Figueiredo, J. B. and A. d. Haan (eds.) (1998). *Social Exclusion: An ILO Perspective*. Geneva, ILO.
- Finkelstein, V. (1992). "Issues in the Terminology of Disability: A Synopsis." Paper submitted to the Open University Advisory Committee on Students with Disabilities.
- _____ (1998a). Emancipating Disability Studies. *The Disability Reader: Social Science Perspectives*. T. Shakespeare. London, Cassell.
- _____ (1998b). Philosophy and Vision of Community Care. *Proposed Community Care System by Disabled Persons: Human Care Association*. Tokyo, Human Care Association.
- Freire, P. and I. Shor (1987). *A Pedagogy for Liberation: Dialogues on Transforming Education*. London, Macmillan.
- French, S. (1997). Disability, Impairment or Something in Between? *Disabling Barriers: Enabling Environments*. J. Swain, V. Finkelstein, S. French and M. Oliver. London, Sage Publication.
- Gilson, S. and E. Depoy (2000). "Multiculturalism and Disability: A Critical Perspective." *Disability & Society* 15(2): 207-18.
- Ginneken, W. V. (1998). Including Informal Sector Workers through Social Security. *Social Exclusion: An ILO Perspective*. J. B. Figueiredo and A. D. Haan. Geneva, ILO.
- Glynn, R. (1996). *Community Based Rehabilitation: An Appropriate Approach of Rehabilitation Services Delivery to People with Disabilities in Remote Aboriginal Communities, A Literature Review*. Material for the training modules for community based rehabilitation workers in remote aboriginal communities, RHSET project report.
- Gore, C. (1995). Introduction: Markets, Citizenship and Social Exclusion. *Social Exclusion: Rhetoric, Reality, Responses*. G. Rodgers, C. Gore and J. B. Figueiredo. Geneva, ILO.
- Groce, N. (1985). *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard*. Harvard, Harvard University Press.
- Hamzetta, B. O. (2004). Disabilities, Accidents and Social Opportunities in Mauritania. Paper presented at the 4th Conference on the Capability Approach: Enhancing Human Security, held at University of Pavia, Italy on 5-7 September 2003.
- Harriss-White, B. (2003). Poverty and Disability: With Special Reference to Rural South Asia. Paper presented at the International Conference, "Staying

- Poor: Chronic Poverty and Development Policy”, at IDPM, University of Manchester, 7-9 April 2003.
- Harris, A. and S. Enfield (2003). *Disability, Equality and Human Rights: A Training Manual for Development and Humanitarian Organisations*. Oxford, Oxfam.
- Hewitt, T. and I. Smyth (1992). *Is the World Overpopulated? Poverty and Development in the 1990s*. T. Allen and A. Thomas. Oxford, Oxford University Press and Open University.
- Houston, S. (2004). “The Centrality of Impairment in the Empowerment of People with Severe Physical Impairments: Independent Living and the Threat of Incarceration: A Human Right.” *Disability & Society* 19(4): 307-21.
- Hughes, B. (1999). “The Constitution of Impairment: Modernity and the Aesthetic of Oppression.” *Disability & Society* 14(2): 155-72.
- Hurst, R. (1998). ICIDH Revision. Paper presented at the JSRD Meeting held at Tokyo, 27-28 March 1998.
- (2003). “The International Disability Rights Movement and the ICF.” *Disability & Rehabilitation* 25(11): 572-76.
- Ilgan, V. (2005). Breaking the Barriers: Enabling Children with Disabilities in the Philippines. <http://www1.worldbank.org/devoutreach/july05/article.asp?id=318> (accessed on 30 March 2006).
- Ingstad, B. (1995). *Mpho ya Modima – A Gift from God: Perspectives on “Attitudes” towards Disabled Persons*. *Disability and Culture*. B. Ingstad and S. R. Whyte. London, University of California Press.
- (2001). Disability in the Developing World. *Handbook of Disability Studies*. G. Albrecht, K. Seelman and M. Bury. Thousand Oaks, California, Sage Publications.
- Ingstad, B. and S. R. Whyte (1995). *Disability and Culture*. Berkeley, University of California Press.
- International Disability Foundation (1999). *The World Disability Report: Disability '99*. Geneva, Author.
- International Institute for Labour Studies (1996). *Social Exclusion and Anti-Poverty Strategies*. Geneva, Author.
- Ishikawa, J. and T. Kuramoto (eds.) (2002). *Syogaigaku no Syucho [Claim of Disability Studies]*. Tokyo, Akashi syoten.
- Ishikawa, J. and O. Nagase, Eds. (1999). *Syogaigaku heno Syotai [Introduction to Disability Studies]*. Tokyo, Akashi syoten.
- Iwasaki, S. (1997a). “Handicap Jyokyo wo Donoyouni Hyoka sureba yoika [How to Assess Condition of Handicap].” *Seishin syogai to Rehabilitation* 1(2): 102-7.

- _____ (1997b). "Syakai Fukushi to Jiyugenri no Kankei nitsuite [Social Welfare and Principle of Freedom]." *Syakai Hukusi Gaku* 38(1): 45-64.
- _____ (1998). "Syakai Fukuhi no Ningenkan to Senzai-noryoku Approach [View of Humanity and Capability Approach]." *Tokyo Toritsu Daigaku Zinbun-gakubu-ho* 291: 49-68.
- Jackson, C. (1999). "Social Exclusion and Gender: Does One Size Fit All?" *The European Journal of Development Research* 11(1): 125-46.
- Jensen, H. (2001). Amartya Sen as a Smithesquely Worldly Philosopher: or Who Needs Sen When We Have Smith? Paper presented at the Conference on Justice and Poverty held at Cambridge, 5-6 June 2001.
- Kanameda, H. (1999). *Syougaisya Sabetsu no Syakaigaku [Sociology of Discrimination of Disabled People]*. Tokyo, Iwanami Syoten.
- Kimura, H. (2000). Ro Bunka to Ro Community [The Deaf Culture and the Deaf Community]. *Syogai-gaku wo Kataru [Discussion on Disability Studies]*. T. Kuramoto and O. Nagase. Tokyo, Space 96.
- Kopec, J. (1995). "Concepts of Disability: The Activity Space Model." *Social Science & Medicine* 40(5): 649-56.
- Kuno, K. and D. Seddon (2003). *Kaihatsu niokeru Syogaisya-bunya no Twin-track Approach no Zitsugen ni Mukete [A Study on Twin-track Approach in Disability and Development]*. Tokyo, Japan International Cooperation Agency.
- Kuramoto, T. (1999). Ikei no Paradox [Paradox of Difference]. *Syogai-gaku heno Syotai [Invitation to Disability Studies]*. J. Ishikawa and O. Nagase. Tokyo, Akashi-syoten.
- Lane, H. (1995). "Constructions of Deafness." *Disability & Society* 10(2): 171-90.
- Lang, R. (1998). "A Critique of the Disability Movement." *Asia Pacific Disability Rehabilitation Journal* 9(1): 4-8.
- Lang, R. and D. Seddon (1999). "Disability and Development Studies: Towards an Integrated Approach." Paper presented at the Development Studies Association (DSA) Annual Conference, held on 12-14 September, at University of Bath.
- Llewellyn, A. and K. Hogan (2000). "The Use and Abuse of Models of Disability." *Disability & Society* 15(1): 157-65.
- Lloyd, M. (1992). "Does She Boil Eggs? Towards a Feminist Model of Disability." *Disability, Handicap & Society* 7(3): 207-21.
- Lukes, S. (1993). *Power: A Radical Review*. London, The Macmillan Press.
- Malinga, J. (2003). The African View of Independent Living. <http://www.independentliving.org/docs6/malinga2003.html> (accessed on 1 April 2006).

- Manderson, L. (2002). Comments: Capabilities and Disabilities: Justice for Mentally Disabled Citizens. Delivered at Australian National University, Canberra, 12-14 November 2002.
- Mitra, S. (2003). The Capability Approach of Disability. Paper presented at the 3rd Conference on the Capability Approach: From Sustainable Development to Sustainable Freedom, held at University of Pavia, Italy on 7-9 September 2003.
- Morris, J. (1992). "Personal and Political: A Feminist Perspective on Researching Physical Disability." *Disability & Society* 7(2): 157-66.
- _____. (1997). *Gender and Disability. Disabling Barriers: Enabling Environments*. J. Swain, V. Finkelstein, S. French and M. Oliver. London, Sage Publication.
- Nagase, O. (1995). Difference, Equality and Disabled People: Disability Rights and Disability Culture. Master thesis submitted to the Institute of Social Studies, Hague.
- _____. (1996a). "Definition of Disability and Disabled Person: An Example in Britain (Part 1)." *Normalisation* (6): 61-3.
- _____. (1996b). "Definition of Disability and Disabled Person: An Example in Britain (Part 2)." *Normalisation* (10): 39-42.
- Nakanishi, Y. (1996). *Azia no Syogaisya [Disabled People in Asia]*. Tokyo, Gendai Syokan.
- Nelson, N. and S. Wright (1997a). Participation and Power. *Power and the Participatory Development: Theory and Practice*. N. Nelson and S. Wright. London, Intermediate Technology Publication.
- _____. (1997b). *Power and the Participatory Development: Theory and Practice*. London, Intermediate Technology Publication.
- Nussbaum, M. (2003). Capabilities and Disabilities: Justice for Mentally Disabled Citizens. Paper presented at The Tanner Lectures on Human Value held at Australian National University on 12-13 November 2003.
- Nussbaum, M. and A. Sen (1993). *The Quality of Life: A Study Prepared for the World Institute for Development Economics Research (WIDER) of the United Nations University*. Oxford, Oxford University Press.
- Oliver, M. (1990). The Individual and Social Models of Disability. Paper presented at Joint Workshop of the Living Options Group and the Research Unit of the Royal College of Physicians on 23 July 1990.
- _____. (1994). Redefining Disability: A Challenge to Research. *Disabling Barriers – Enabling Environments*. J. Swain, et al. London, SAGE Publications.
- _____. (1996). *Understanding Disability: From Theory to Practice*. London, Macmillan.
- Oliver, M. and C. Barnes (1997). "All We are Saying is Give Disabled Researchers a Chance." *Disability & Society* 12(5): 811-3.

- Ooi, G. (1989a). *The Disabled as a Neglected Minority. Justice not Charity*. D. Jayasooria. Kuala Lumpur, Centre for Community Studies Bhd.
- Pfeiffer, D. (1998). "The ICIDH and the Need for its Revision." *Disability & Society* 13(4): 503-23.
- _____. (2000). "The Devils are in the Details: The ICIDH2 and the Disability Movement." *Disability & Society* 15(7): 1079-82.
- _____. (2001). *The Conceptualisation of Disability. Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go*. S. Barnartt and B. Altman. Oxford, Elsevier Science.
- Porter, F. (2000). "Social Exclusion: What's in a Name?" *Development in Practice* 10(1): 76-81.
- Pretty, J. N. (1995). "Participatory Learning for Sustainable Agriculture." *World Development* 23: 1247-63.
- Qizilbash, M. (1996). "Ethical Development." *World Development* 24(7): 1209-21.
- _____. (2001). *Amartya Sen's Capability View: Insightful Sketch or Distorted Picture?* Norwich, School of Economic and Social Studies University of East Anglia.
- Robeyns, I. (2003). *The Capability Approach: An Interdisciplinary Introduction*. Revised version of a paper prepared for the training course preceding the 3rd International Conference on the Capability Approach, Pavia, Italy, on 6 September 2003.
- _____. (2004). *Capability. International Encyclopaedia of Social Policy*. T. Fitzpatrick, N. Menning, G. Pascall, J. Midgley and H.-J. Kwon. <http://www.ingridrobeyns.nl/Downloads/capability.pdf> (accessed on 4 December 2004).
- Rodgers, G., *et al.* (1995). *Social Exclusion: Rhetoric, Reality, Responses*. Geneva, ILO.
- Rogaly, B., *et al.* (1999). *Poverty, Social Exclusion and Micro Finance in Britain*. Oxford, Oxfam.
- Rowlands, J. (1995). "Empowerment Examined." *Development in Practice* 5(2): 101-6.
- _____. (1997). *Questioning Empowerment: Working with Women in Honduras*. Oxford, Oxfam.
- Seddon, D., *et al.* (2001). *Mainstreaming Disability Issues into Development Studies: In Theory and Practice*. Paper presented at the 14th Annual Meeting of the Disability Studies Association, Winnipeg, Canada.
- Sen, A. (1987). *The Standard of Living. The Standard of Living*. G. Hawthorn. Cambridge, Cambridge University Press.
- _____. (1992). *Inequality Re-examined*. Oxford, Clarendon Press.

- _____ (1993). Capability and Well-Being. *The Quality of Life*. M. Nussbaum and A. Sen. Oxford, Clarendon Press.
- _____ (1999). *Development as Freedom*. Oxford, Oxford University Press.
- _____ (2000). Social Exclusion: Concept, Application, and Scrutiny. *Social Development Paper No. 1*. Manila, Asian Development Bank.
- _____ (2004). Disability and Justice. Speech presented at the World Bank on 3rd December, http://siteresources.worldbank.org/DISABILITY/214576-1092421729901/20291152/Amartya_Sen_Speech.doc Keynote (accessed on 4 April 2005).
- Shakespeare, T. (1994). "Cultural Representation of Disabled People: Dustbins for Disavowal?" *Disability & Society* 9(3): 283-99.
- Sharma, M. and S. Deepak (2002). "A Case Study of the Community Based Rehabilitation Programme in Mongolia." *Asia Pacific Disability Rehabilitation Journal* 13(1): 11-8.
- Silver, H. (1995). Reconceptualizing Social Disadvantage: Three Paradigms of Social Exclusion. *Social Exclusion: Rhetoric, Reality, Responses*. G. Rodgers, C. Gore and J. B. Figueiredo. Geneva, ILO.
- Swain, J. and S. French (2000). "Towards an Affirmation Model of Disability." *Disability & Society* 15(4): 569-82.
- Swedish International Development Authority (1995). *Poverty and Disability: A Position Paper*. n.p., Author.
- Terzi, L. (2003). A Capability Perspective on Impairment and Disability: Towards Social Justice in Education. Paper presented at the 3rd Conference on the Capability Approach: From Sustainable Development to Sustainable Freedom, held at University of Pavia, Italy on 7-9 September 2003.
- Union of the Physically Impaired against Segregation (1975). Fundamental Principles of Disability. <http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htmf> (accessed on 21 April 2004).
- United Nations (1982). World Programme of Action Concerning Disabled Persons. <http://www.un.org/esa/socdev/enable/diswpa00.htm> (accessed on 10 December 2003).
- _____ (1993). Standard Rules on the Equalisation of Opportunities for People with Disabilities, <http://www.un.org/esa/socdev/enable/dissre00.htm> (accessed on 12 December 2004).
- _____ (1995). World Summit for Social Development: The Copenhagen Declaration and Programme of Action. New York, Author.
- _____ (1999). Report of the United Nations Consultative Expert Group Meeting on International Norms and Standards Relating to Disability. www.un.org/esa/socdev/disberk0.htm (accessed on 28 December 1999).

- _____ (2000). The International Year of Disabled Persons 1981. <http://www.un.org/esa/socdev/enable/disiydp.htm> (accessed on 4 December 2004).
- United Nations Development Programme (1997). *Human Development Report*. Oxford, Oxford University Press.
- United Nations Educational Scientific and Cultural Organisation (1994). *The Salamanca Statement and Framework for Action on Special Needs Education*. Salamanca, Author.
- United Nations Research Institute for Social Development (1994). *Social Integration: Approaches and Issues*. Geneva, Author.
- Ustun, T. B. (1998a). Classification of Functioning and Disablement: Revising ICIDH. Paper presented at the JSRD Meeting held at Tokyo, 27-28 March 1998.
- _____ (1998b). *Towards a Common Language for Functioning and Disablement: ICIDH-2 The International Classification of Impairments, Activities, and Participation*. Geneva, WHO.
- _____ (2001). *Disability and Culture: Universalism and Diversity*. Seattle, Hogrefe & Huber on behalf of the World Health Organisation.
- Ustun, T. B., et al. (1998). "A Reply to David Pfeiffer 'The ICIDH and the Need for Its Revision'." *Disability & Society* 13(5): 829-31.
- Venkatesan, S. A. (2004). "Survey of Knowledge and Opinion on Rights Immunities and Privileges for Persons with Mental Retardation." *Asia Pacific Disability Rehabilitation Journal* 15(1): 59-68.
- Welch, P. (2002). Applying the Capability Approach in Examining Disability, Poverty, and Gender. Paper presented at the conference on Promoting Women's Capabilities: Examining Nussbaum's Capabilities Approach, held at University of Cambridge, on 9-10 September 2002.
- _____ (2003). Disability, Poverty, and Development: An Application of the Capabilities Approach in Nepal. Paper presented at the 3rd Conference on the Capability Approach: From Sustainable Development to Sustainable Freedom, held at University of Pavia, Italy on 7-9 September 2003.
- _____ (2004). Ethical Implications on Disability of the Capability Approach versus DALYs. Paper presented at the 4th Conference on the Capability Approach: Enhancing Human Security, held at University of Pavia, Italy on 5-7 September 2003.
- Werner, D. (1992). How to Strengthen the Role of Disabled People in a CBR Programme. Paper presented at the Seminar on Community-Based Rehabilitation (CBR): RI Pre-Congress Seminar in Limuru, Kenya, 31 August - 3 September 1992, ICTA.
- _____ (1994). Strengthening the Role of Disabled Persons in Community

- Based Rehabilitation Programmes. Paper presented at the Workshop on Community Based Rehabilitation held at Solo, Indonesia, 22-26 November 1994.
- _____ (1998). *Nothing about Us without Us: Developing Innovative Technologies for, by and with Disabled Persons*. Palo Alto, Health Wrights.
- White, S. and R. Tiongco (1997). *Doing Theology and Development: Meeting the Challenge of Poverty*. Edinburgh, Saint Andrew Press.
- World Bank (2000). *World Development Report 1999/2000: Entering the 21st Century*. New York, Oxford University Press.
- World Health Organisation (1980). *International Classification of Impairments, Disabilities, and Handicaps*. Geneva, Author.
- _____ (1998). The Concepts of Disablement and Functioning. www.who.ch/icidh (accessed on 2 March 2000).
- _____ (2002). International Classification of Functioning, Disability and Health. <http://www3.who.int/icf/icftemplate.cfm> (accessed on 3 May 2004).
- Yamamori, T. (2003). Constructive Universalism: Sen and Sensitivity to Difference. Paper presented at the 3rd Conference on the Capability Approach: From Sustainable Development to Sustainable Freedom, held at University of Pavia, Italy on 7-9 September.
- Yeo, R. (2002). *Chronic Poverty and Disability*. Manchester, ADD, Chronic Poverty Research Centre, IDPM.
- Zaidi, A. and T. Burchardt (2004). Comparing Incomes When Needs Differ: Equivalisation for the Extra Costs of Disability in the UK. Paper presented at the 4th International Conference on the Capability Approach: Enhancing Human Security, held at University of Pavia, Italy on 5-7 September.