

Symposium on Community-Based Rehabilitation

Moderator: Dr. Wim van Brakel

Programme:

- Short presentations
 1. Dr. Wim van Brakel (Intro to CBR + stigma workshop)
 2. Ms. Jannine Ebenso (SHOs in rehabilitation)
 3. Ms. Birke Nigatu (the experience of the ENAELP)
 4. Dr. Denis Byamungu (CBR and community participation)
 5. Dr. Sunil Deepak (Integrating leprosy rehabilitation and CBR)
- Panel discussion with questions from the floor

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Disability

- Estimated 600 million people world-wide
- 1.5-2 million people with leprosy-related disability
- Only small % have access to rehabilitation
- CBR is strategy to increase coverage of and access to rehabilitation
- Of people with disability:
 - 1/3 need no rehabilitation
 - 1/3 can be helped through CBR alone
 - 1/3 need specialised referral services.

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Definition of CBR

"A strategy within community development for the rehabilitation, equalization of opportunities, and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services"

Source: UN, WHO, and ILO. Joint position paper, 1994. Community Based Rehabilitation for and with people with disabilities

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CBR characteristics

- CBR and 'institution-based rehabilitation' complementary
- Multi-disciplinary and multi-sectoral
- No one 'method' of 'doing' CBR
- Empowers people
- Participatory.

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Psychosocial consequences of leprosy: Workshop on Research on health-related Stigma and Discrimination

Soesterberg, Netherlands
29 Nov – 2 Dec 2004

Wim H. van Brakel

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Participants

- 71 experts and researchers, including people affected, representing 20 countries
- Major public health fields: leprosy, HIV/AIDS, tuberculosis, mental health, epilepsy, physical disability, Buruli ulcer

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Problem statement

- Stigma has major impact on psychosocial life of individuals, families and communities
- Stigma leads to violation of human rights
- Strong negative consequences for public health programmes
- No widely accepted model or standard definition of stigma
- Comprehensive, strategic approach to interventions missing.

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Problem statement - continued

- Impact of stigma reduction activities often not measured
→ effectiveness not known
- Stigma measurement fragmented and often condition-specific
- No generic set of instruments available for comprehensive assessment of stigma.

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Impact of stigma on the individual

	Lep	H/A	TB	MI	Ep	Dis
Stress and anxiety, depression, etc.	●	●	●	●	●	●
Problems in marriage or getting married	●	●		●	●	●
Problems in social relationships	●	●	●	●	●	●
Problems with employment	●	●		●	●	●
Problems with education (own or children)	●	●			●	●
Concealment	●	●	●	●	●	
Isolation	●	●		●	●	●
Increased disability / worse prognosis	●	●	●	●		
Increased gender differences	●	●	●	●		●
Empowerment (as a response)	●	●		●	●	●

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Impact on public health programmes

	Lep	H/A	TB	MI	Ep	Dis
Delay in presentation	●	●	●	●		●
Failure of prevention / continued transmission	●	●	●			
More complicated, more expensive treatment	●	●	●	●		●
Poor adherence and default	●	●	●	●		
Risk of drug resistance	●	●	●			
Poor image of the public health services	●	●	●	●		

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Why a stigma model?

- To help in understanding the dynamics of stigma as a process
- To guide measurement of stigma
- To help target interventions.

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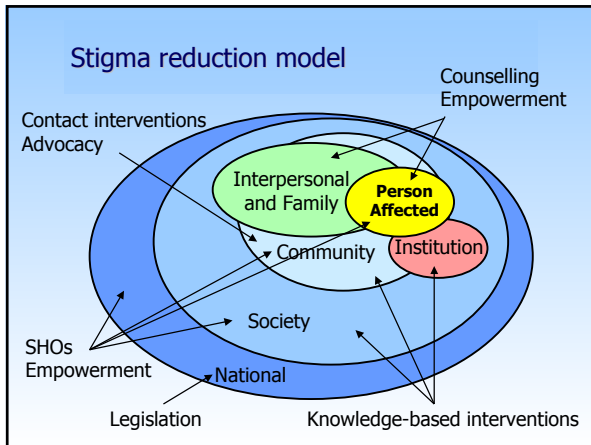


Types of stigma

- Enacted stigma
- Perceived stigma
- Self- or internalised stigma.

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Why measure stigma?

- To understand the nature
- To document the extent
- To measure change.

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What do we want to measure?

- Impact on the person affected
- Attitudes and practices towards people affected
 - Community
 - Specific groups, e.g. health and social services
- Legislation
- Image portrayed of affected people.

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Urgent need for international collaboration

International Consortium for Research and Action on health-related Stigma (ICRAS)

- Open to institutions, organisations and individuals working on
 - Stigma
 - Discrimination
 - Social exclusion
- Forum for discussion
- Exchange of knowledge, expertise, etc.
- Resource for 'tools' for stigma reduction

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Conclusions

- Data on stigma are urgently needed
- Experiences and consequences of stigma very similar in different conditions and cultures
- Common strategies and interventions for stigma reduction appear feasible
- Database of available stigma assessment instruments should be developed
- Possible to develop a set of generic instruments to measure stigma based on existing instruments
- International consortium being set up.

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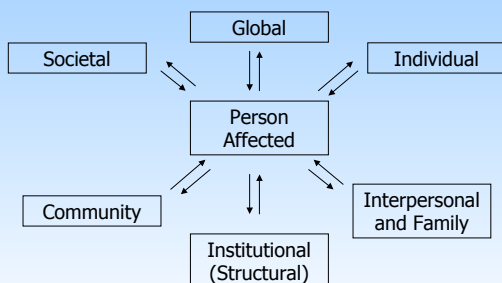
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Intervention Framework Levels of Intervention



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Promising interventions

- Individual level
 - Counselling
 - Empowerment
- Community level
 - Contact interventions
 - Knowledge-based interventions
 - Advocacy
- National level
 - Legislation
 - Empowerment / organisation of people affected.

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Measuring public attitudes

- Explanatory Model Interview Catalogue (EMIC) Weiss et al.
- AIDS Attitude Scale – General (AAS-G) Froman & Owen
- Siyam'kela indicator set Policy Project South Africa
- USAID Indicator set IWG-S&D
- Community Attitudes towards Mental Illness (CAMI) Taylor & Dear
- Attribution Questionnaire Corrigan et al.
- Community attitude scales Angermeyer & Matschinger

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Measuring actual discrimination

- Protocol for identification of discrimination against PLWH UNAIDS
- Siyam'kela indicator set Policy Project South Africa
- USAID Indicator set IWG-S&D

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Measuring perceived stigma

- HIV Stigma Scale Berger et al.
- Internalised Stigma of Mental Illness scale (ISMI) Ritsher et al.
- Stigma scale Jacoby et al.
- Children and Parents epilepsy scale Austin et al.

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Impact on person affected

- Participation Scale van Brakel et al.
- Siyam'kela indicator set Policy Project South Africa
- Self-Efficacy Scale Tedman et al.
- QOLIE-AD-48 Cramer et al.
- Children's Attitude Towards Illness Scale (CATIS) Austin & Huberty
- Impact on Participation and Autonomy Questionnaire (IPAQ) Cardol et al.
- Assessment of Life Habits (Life-H) Noreau et al.
- Craig Handicap Assessment Reporting Technique (CHART) Whiteneck et al.

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Stigmatising (health) services

- Protocol for identification of discrimination against PLWH UNAIDS
- Siyam'kela indicator set Policy Project South Africa
- USAID Indicator set IWG-S&D

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Portraying a positive or negative image

- Protocol for identification of discrimination against PLWH UNAIDS

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Most common items - 1

	Disciplines
Interpersonal interactions and relationships	Problems in marriage 7
	People try to conceal the condition 7
	People avoid someone with the condition 6
	Problems to get married 5
	Affected person loses respect 5
Major life areas	Affected person not allowed to be or play with children 4
	Relationship with friends affected negatively 4
	Reduced opportunity to find work 5
	Loosing work or reduced career prospects 4

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Most common items - 2

	Disciplines
Community, social and civic life	Less visiting or being visited by friends, family and others 5
	Reduced social activity 4
Self-esteem	I'm not as good as others / thinking less of oneself 5
Perceived stigma	Others think less of a person affected 4
Fear	People are afraid of persons with this condition 4
Shame/embarrassment	This condition is associated with shame or embarrassment 7
Pity	People feel sorry for / pity a person with this condition 4

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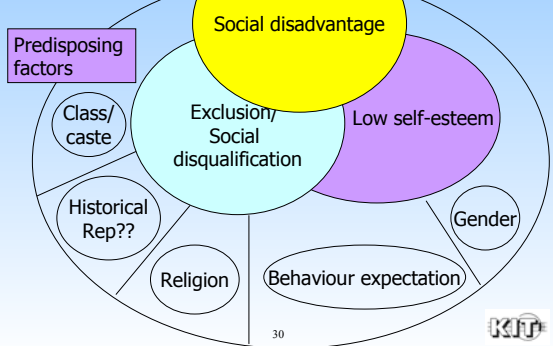
Objectives

- To review work done to date on the topic of health-related stigma
 - Common features between conditions and cultures
 - Condition and culture-specific features
- To try to identify gaps in our current knowledge
- To develop a working model of health-related stigma
- To draw up a list of specific research questions
 - Models and definitions of stigma
 - Strategies and interventions for stigma reduction
 - Assessment of stigma and discrimination
- To draw up an agenda for future research.

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Working Model of Stigma



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