

International Perspectives on Spinal Cord Injury, IPSCI



A collaborative WHO
publication project



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Overview of presentation

- What is IPSCI?
- Why is it so important?
- What are the objectives & aims?
- Who is the target audience?

- Who are the people involved?
- What is the content?

- Where are we now?
- ESCIF & IPSCI?
- What are the next steps & targets?

What is IPSCI?

- IPSCI is a joint WHO, professional organization and disability people's organization project.
- It follows the WHO World Report on Disability and Rehabilitation (WRDR).
- It presents a global picture of spinal cord injury (SCI)
- The scope is the entire lived experience of SCI.
- IPSCI aims to inform an agenda for future work.

Why is it so important ?



Objectives

- To summarize existing information on SCI and the lived experience of persons with SCI.
- To document the evidence base demonstrating the gap between what exists and what is required.
- To make recommendations for future research and action - based on the best available scientific evidence.

Specific aims

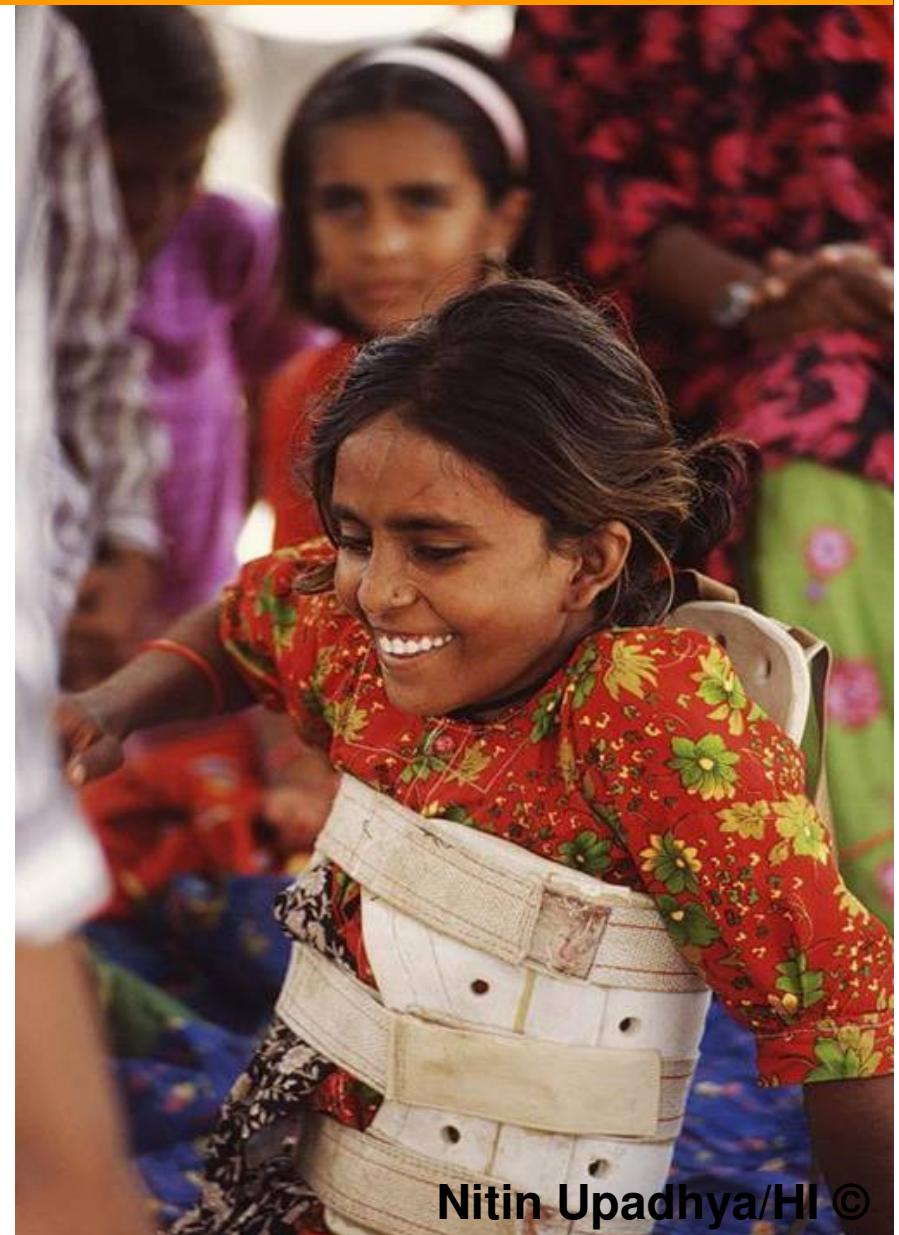
The specific aims are to:

- raise awareness
- identify gaps
- inform research agendas
- raise political will and attention
- facilitate political action
- inform review of policies and services in place

→ involve people with SCI

Target Audience

- Policy Makers
- Service providers, insurers
- Disability and development actors
- People with SCI and their families
- Media
- Donors
- Practitioners
- Academics
- Broader community



Who are the people involved?



World Health
Organization

Disability and
Rehabilitation Team,
Alana Officer



Wagih ElMasri,
Fin Biering-Sørensen



Swiss
Paraplegic
Research

Jerome Bickenbach,
IPSCI Editor in Chief



Jane Horsewell
Daniel Joggi
Pietro Barbieri
Gelu Onose
Jiri Kriz

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Who are the people involved?

Advisory Committee

Members

- Professional organizations (e.g. ISCoS, WCPT, WFOT)
- Disability People's Organizations (ESCIF, SPV, PARAQUOD, PVA, Disabled People's International)
- Strong interdisciplinary and global geographic orientation.
- Diverse constituency of scholars and practitioners.

Tasks

- Comment on and review first draft
- Lend technical, logistical and political support for launch, dissemination and implementation

Editorial Committee

Members

- Practitioners and academics from around the world
- Each chapter has at least one Chapter Editor

Tasks

- Coordinate the technical development of the report
- Ensure the highest possible quality of its content.
- Chapter Editors are assisted by a team of experts from around the world.

Authors and Contributors

Members

- Up to 70 Practitioners, academics, people with SCI & advocates

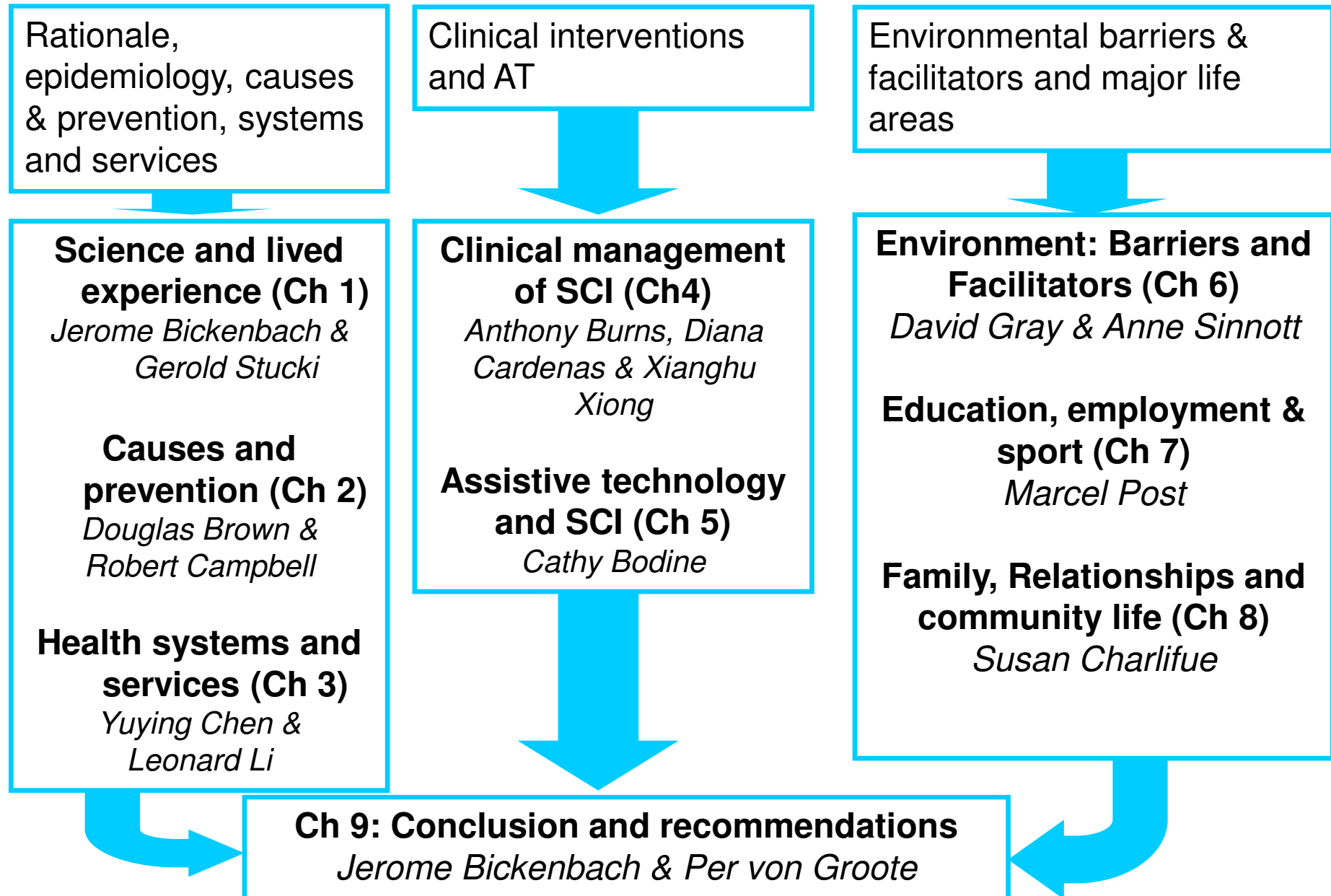
Tasks

- To write sections, paragraphs, vignettes, case boxes

2nd Editorial Committee meeting



Content



Where are we now?

- We are, before completion of a first complete draft
- Some chapters are already in a multilayer review and rewrite stage
- We are, in the process of exchanging ideas on and planning how to best:
 - disseminate
&
• implement IPSCI

Implementation

Implementation = knowledge transfer into action

This means to use IPSCI to facilitate:

1. awareness raising
2. agenda setting
3. research to close knowledge gaps
4. policy

ESCIF and IPSCI

- Contribution to IPSCI content
 - text, case boxes
 - review
 - input of expert knowledge and *the lived experience*
- disseminate through ESCIF &
- first implementation ideas for discussion:
 - International Labour market Integration Assessment in Spinal Cord Injury (ILIAS)
 - The objective is to assess the labour market integration of people with SCI in different countries worldwide in order to examine potential determinants and consequences.
 - Central registries project

Next steps & targets

- Extensive review
- Rewrite
- Dissemination / presentation (DMGP, SASCA)
- Implementation plan
- Regional workshop at ISCoS New Delhi, October 2010
- Launch at ISCoS part of joint ASIA meeting 2011 in Washington DC

Thank you for your attention!

Comments, questions?

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