International Perspectives on Spinal Cord Injury, IPSCI

A collaborative WHO publication project
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Overview of presentation

• 30 minute presentation / 15 minutes for questions

I. Reminder: what is IPSCI?

II. Developments since IPSCI presentation in Lobbach, May 2010

III. Preview current content of IPSCI
   a. When will the final IPSCI report be presented?

IV. What can be done with IPSCI after its launch?

V. How can ESCIF assist?

VI. Our efforts to assist implementation
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I. Reminder: what is IPSCI?

• The IPSCI report is a joint WHO-ISCoS, professional organization and disability people’s organization project

• It presents a global picture of spinal cord injury (SCI) in a single WHO report

• It follows the WHO World Report on Disability (WRD)

• The scope is the entire lived experience of SCI

• IPSCI aims to inform an agenda for future work
Objectives

• To summarize existing information on SCI and the lived experience of persons with SCI on a global perspective

• To document what we know about SCI and to document gaps in our understanding;

• 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 focus attention
• facilitate political action
• inform review of policies and services in place
Target Audience

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

• IPSCI is being developed in partnership with professional organizations and organizations of persons living with SCI from around the world

• Editorial teams coordinate the technical development

• Expert reviewers assure the quality and relevance of the content

• People with SCI are represented at all levels
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II. Developments since IPSCI presentation in Lobbach, May 2010

• Completion of first draft
• Delhi consultation at ISCoS 2010, New Delhi
• Early 2011 extensive WHO review
  – New chapter structure
  – Creation of epidemiological chapter
• Redraft by author teams until August

• Continuous work on implementation plan, strategy
• WRD launch, dissemination and implementation
  – as a case in point for implementation of a report
  – implications of reception on IPSCI
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III. Content outline

Rationale, global and regional data, prevention

Science and lived experience (Ch 1)
Epidemiology of SCI (Ch 2)
Prevention (Ch 3)

Medical needs, related systems and services and AT

Health needs, systems and services (Ch 4)
Assistive technology and SCI (Ch 5)

Environmental barriers & facilitators and major life areas

Environment: Barriers and Facilitators (Ch 6)
Education, employment (Ch 7)
Family, Relationships and community life (Ch 8)

Ch 9: Conclusion and recommendations
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*Implementation strategies*

- **Dissemination**
  - IPSCI needs to be made known to relevant audiences

- **Analysis**
  - Identify target audience and issue

- **Lobbying**
  - Use IPSCI to enhance visibility of concern

- **Implementation**
  - Advocate for suggested solution and facilitate change

**Actors** = ESCIF
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Dissemination

- ESCIF and National Society Newsletters and Websites
  - Announcements of launch and activities
  - Official ESCIF statement, endorsement

- Journals (e.g. Spinal Cord)
  - Analysis of IPSCI
  - ESCIF statement
  - Call for specific action

Lobbying for change

- Identify actors within ESCIF – working group
- Match IPSCI recommendations to actions
- Identify target audience, specific individuals
- Create a monitoring/reporting mechanism
V. How can ESCIF assist?

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VI. Our efforts to assist implementation

We at SPF are looking at ways a report like IPSCI can be implemented to then inform/assist actors such as ESCIF

- Review of extensive implementation science literature
  - Challenge → no research on implementation of political recommendations as in WHO reports
- Creating an IPSCI implementation plan
  - Grading recommendations (recommendation matrix)
  - Linking level of recommendation to implementation strategy
  - Survey of implementation needs and expectations to gather information on communication pathways and implementation setting
- Creating checklists to inform implementation actors
- Help monitor the outcomes

Evidence informed policy
Comparing concepts and strategies

Recommendation characteristics

Outer setting

Inner setting

Characteristics of individuals

Process

(Source: Damschroder et al 2009)
Analysing existing implementation models

### Finding and Using Research Evidence

#### Check that a problem is

1. **What is the problem?** Local data
   - http://www.jen.mn/for provincial states
   - http://www.nhl.aa for national databases
2. **How did the problem come to attention and has this process informed the progress of it being addressed?** PubMed ISIR Queries
   - http://www.sln.mn/gov/ahinsa/bikis/search.html
     - Process assessment
     - Performance assessment
3. **What indicators can be used, or collected, to establish the magnitude of the problem and to measure progress in addressing it?** PubMed ISIR Queries
   - http://www.sln.mn/gov/ahinsa/bikis/search.html
     - Qualitative research
4. **What comparisons can be made to establish the magnitude of the problem and to measure progress in addressing it?**

#### Frame the options

1. **What are the appropriate set of options that have been identified to address the problem?**
2. **What are the potential barriers to the successful implementation of the policy?**
3. **What strategies should be considered in order to facilitate the necessary behavioral change among patients/citizens?**
4. **What strategies should be considered in order to facilitate the necessary organizational changes among health workers?**
5. **What strategies should be considered in order to facilitate the necessary system changes?**

#### Implement the option

- Health Systems Evidence for health system arrangements
  - http://www.healthsystemevidence.org
- Cochrane Library for clinical programs, services and drugs
  - http://www.cochranelibrary.com
- Health evidence.ca for public health programs and services
  - http://health-evidence.ca
- Cochrane Library for economic evaluations of any option
  - http://www.cochranelibrary.com
- PubMed ISIR Queries
  - http://www.sln.mn/gov/ahinsa/bikis/search.html
    - Qualitative research

For systematic reviews:

1. What is the quality (AMESTAR) score?
2. How locally applicable are the key messages?

**SUPPORT tools available at:** http://www.health-policy-system.com/supplements/7/21

* “not free” ≠ not free
  + (doctor AND nurse OR pharmacist) ≠ doctor AND nurse OR pharmacist
  + stress = stress OK stress OR stress

Updated by John Lovis on 20/2/2019

**McMaster Health Forum**

www.mcmasterhealthforum.org
Surveying the setting

![Bar chart showing percent agreeing or strongly agreeing in dissemination channel.

- Presentations at scientific conferences
- Online resource & reference collection
- Embedded in ISCoS website
- Embedded in WHO website
- Workshops at scientific conferences
- Scientific journals
- Hard copies sent to other organizations
- E-Mails to ISCoS members
- Newspapers
- Special champions
- E-Mails to other organizations
- Specific IPSCI website
- Hard copies sent to ISCoS members
- Special events
- Purchase

Percent agreeing or strongly agreeing in dissemination channel]
The challenge: recommendations to action

The UN Convention on the Rights of Persons with Disabilities (CRPD) indicates the following areas for action:

**Accessibility** – stop discrimination against people with disabilities when accessing healthcare, health services, health insurance, and life insurance. This includes making the environment accessible.

**Affordability** – ensure that people with disabilities get the same variety, quality, and standard of free and affordable healthcare as other people.

**Availability** – put early intervention and treatment services as close as possible to where people live in their communities.

**Quality** – ensure that health workers give the same quality care to people with disabilities as to others.
Bridging the gap: recommendation to action

- **Proposition:**
  - Implementation checklist to be sent to ESCIF working group in 6-8 months
  - ESCIF working group to discuss how ESCIF wants to use the checklist
  - Meeting of ESCIF working group in a year to calibrate checklist for ESCIF and set implementation agenda
Thank you for your attention!
Comments, questions?

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