

# Employment after spinal cord injury: State of the art and the ILIAS study

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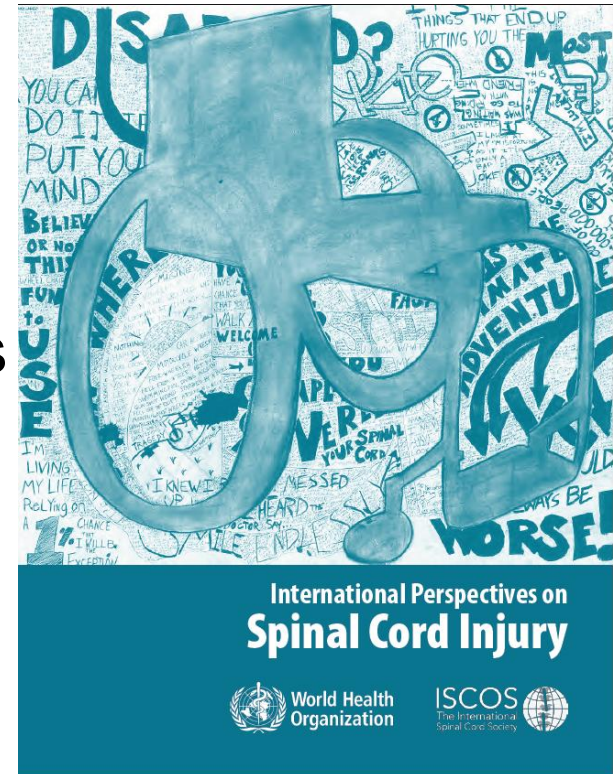
# Employment in pwSCI

“most people with SCI can work and can be productive members of society if there are appropriate work accommodations where required”

“many people with SCI (..) are excluded from work and livelihood opportunities, with the result that they and their families live in poverty and are marginalized from the mainstream of society”

IPSCI report 2013, p. 177

[http://www.who.int/disabilities/policies/spinal\\_cord\\_injury/en/](http://www.who.int/disabilities/policies/spinal_cord_injury/en/)



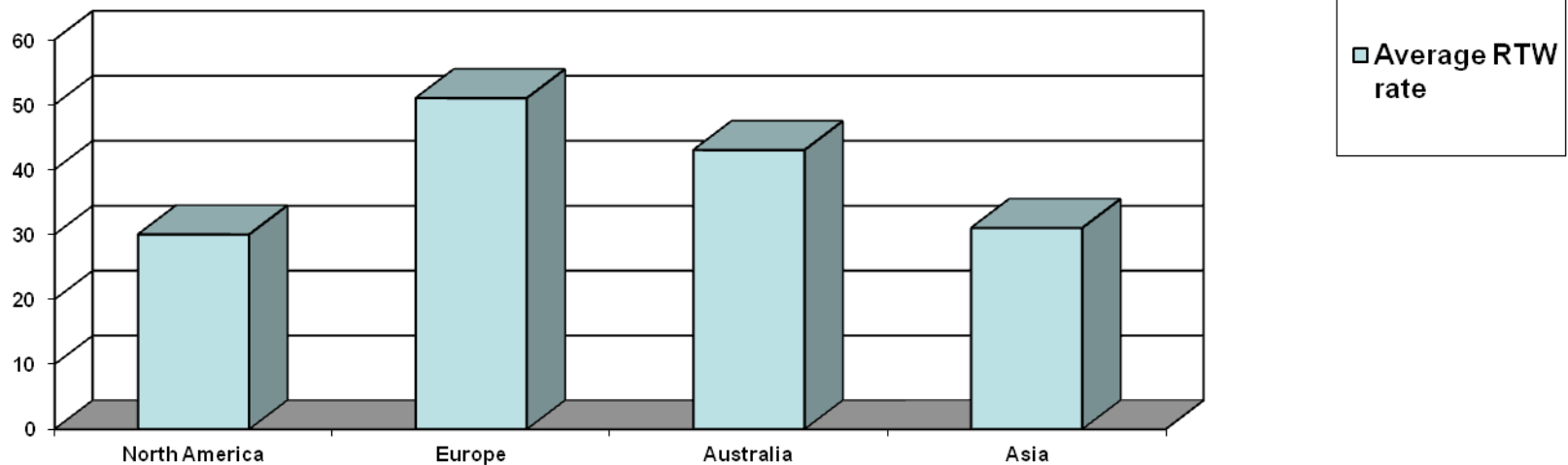
# Benefits of work

- Income
- Social integration
- Self-esteem
- Health / life expectancy
- Adjustment, quality of life

# Persons with disability

- Are more often unemployed
- If employed, work more often part-time
- Are on average older
- Have on average less education
- Are more often poor

# Employment rates of pwSCI across the world



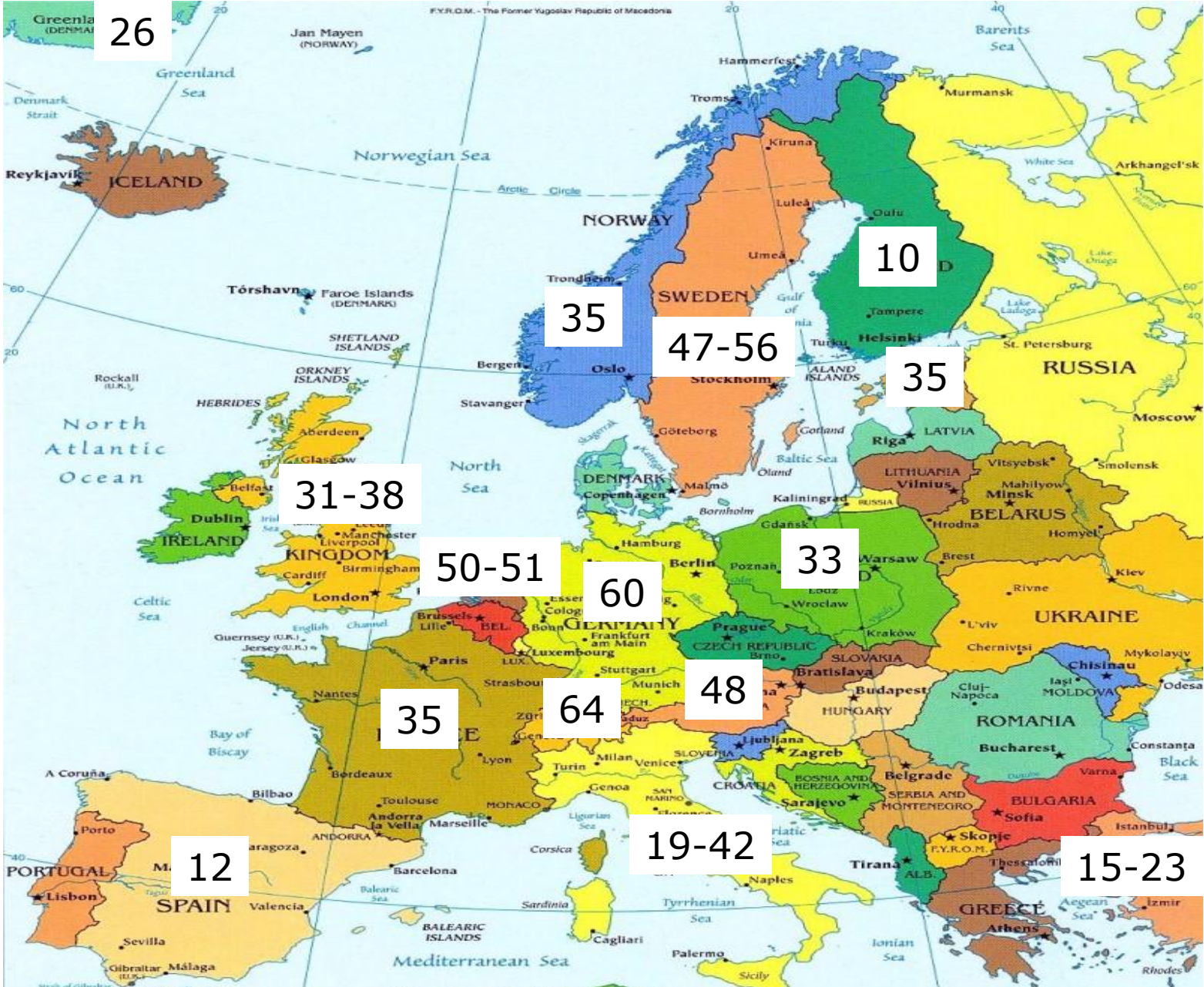
IPSCI Report, 2013; Based on Young and Murphy (2009)

# Factors related to employment

- Demographic
  - Sex, age, race, **education**, employment at onset
- SCI-related
  - Level, completeness, time since injury, **functional status, ability to drive, secondary health conditions**
- Psychological
  - **Motivation, attitude, expectation to RtW**
  - **Locus of control**
  - **Social skills**

Ottomanelli et al, 2009; Lidal et al, 2007

# Employment of pwSCI in Europe



# Limitations of available data

- Lack of data (Eastern and Southern Europe)
- Many small studies
- Diverging definitions of employment
- Diverging populations / inclusion criteria
- Diverging selections of predictors
- *We need international comparative research*



# International Labour market Integration Assessment in SCI (ILIAS)



# ILIAS team

Jan Reinhardt

Switzerland

Håkon Leiulfsrud

Norway

Annelie Leiulfsrud

Norway

Jane Horsewell

Denmark (ESCIF)

Fin Biering-Sørensen

Denmark

Marcel Post

the Netherlands

Funding data collection  
and database:




Local Funding



# History of ILIAS

- 2008 Labour market survey in Switzerland
- 2008 Formation project group
- 2012 Data collection

Employment in persons with spinal cord injury in the Netherlands in 2012: participation, satisfaction, work stress and quality of life.



A.J.C van Wisselingh MD<sup>1</sup>, M.W.M Post PhD<sup>1,2,3</sup>, F.W.A van Asbeck MD PhD<sup>1</sup>

<sup>1</sup>De Hoogstraat Rehabilitation Centre, Utrecht, The Netherlands; <sup>2</sup>University Medical Center Utrecht, Rudolf Magnus Institute of Neuroscience and Center of Excellence for Rehabilitation Medicine, Utrecht, The Netherlands; <sup>3</sup>Center for Rehabilitation, University Medical Center Groningen, The Netherlands

**Work stress and quality of life in persons with disabilities from four European countries: the case of spinal cord injury**

Christine Fekete · Morten Wahrendorf ·  
Jan D. Reinhardt · Marcel W. M. Post ·  
Johannes Siegrist



**Arbeidsparticipatie en arbeidssatisfactie van mensen met een dwarslaesie in Nederland in 2012**

Resultaten van het Nederlandse deel van de studie International Labour market Integration Assessment in Spinal cord injury (ILIAS-NL)



**Labor Market Participation of people with spinal cord injuries in Switzerland: First results from the Swiss Spinal Cord Injury Cohort Study (SwiSCI)**

Jan D Reinhardt<sup>1,2,4</sup>, PhD; Marcel MW Post<sup>1,3</sup>, PhD; Bruno Trezzini<sup>1,4</sup>, PhD; & Martin WG Brinkhof<sup>1,4</sup>, PhD

**Factors explaining employment after a spinal cord injury in Norway: a cross-sectional survey**

Annelie Schedin Leiufrud and Erling Solheim

Target Journal: *Disability and Rehabilitation*

Participation and life satisfaction in aged people with spinal cord injury: does age at onset make a difference?

Marcel W.M. Post, PhD<sup>1,2,3</sup> and Jan D. Reinhardt, PhD<sup>3,4,5</sup>

# ILIAS survey

- Denmark, Netherlands, Norway, Switzerland
- Cross-sectional survey (web+paper/pencil)
- Members SCI consumer organizations
- Data collection in 2012
- Response 132-907; total N=1689 ( $\approx 50\%$ )

# Methods

- Design: Cross-sectional survey
- Subjects:
  - members SCI consumer organizations  
(in Switzerland every person with SCI)
  - At least 18 years of age
- Procedure:
  - Invited through consumer organization
  - Pen/paper or web-based self-report questionnaire  
(Denmark only web-based)
  - Reminder (differed between countries)

# ILIAS SCI International Labour Market Integration Assessment in SCI

EN NO NL DK DE 中文

## Welcome to the ILIAS website!

### Contact

If you have any ideas or questions about the project, please contact [contact@ilias-survey.eu](mailto:contact@ilias-survey.eu)

Contact Telephone  
0041-041-939 6595

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### National contacts

#### Norway

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#### Denmark

Jane Horsewell, MSc  
[jane@ryk.dk](mailto:jane@ryk.dk)

Tlf: 0045 - 39816131

### Support

For any support in completing the questionnaire, please contact the national ILIAS hotline.

### Background

ILIAS is a research project of the European Spinal Cord Injury Federation (ESCIF [www.escif.org](http://www.escif.org)) coordinated by a team of researchers from different European universities. ILIAS realizes that labour market participation of people with SCI is important to their self-realization and self-esteem. It may further have positive effects on their participation in other areas of life as well as on their health.

### Objectives

ILIAS wants to examine why some people with SCI work and others not and which are the consequences for their health, income, and general social integration.

### Implications

ILIAS will for the first time assess the labour market participation of people with SCI in a European context. Welfare systems and vocational rehabilitation can be compared. ILIAS will identify barriers and facilitators of social inclusion. Recommendations for policy and vocational consulting will be derived.

### Project team

Jan D. Reinhardt, PhD; Marcel Post, PhD; Annelie Leiulfsrud, MA; Jane Horsewell, MSc; Hakon Leiulfsrud, PhD; Fin Biering-Soerensen, MD

### Go to the ILIAS survey

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# Contents ILIAS questionnaire

Income, work situation	European Social Survey ( <a href="http://www.ess.eu">www.ess.eu</a> ) EU-Statistics Income Living Conditions
Barriers, satisfaction	Own items
ADL	5 SCIM-items (Catz, 2002)
Sec. Health Conditions	8 no/yes items
Attitudes towards work	Barriers questionnaire (Krause, 2011)
Work stress	Effort-Reward Imbalance (Leineweber, 2010)
Job control	Job Content Questionnaire (Karasek, 1998)
Participation	Frequency USER-participation (Post, 2012)
Life satisfaction	5 WHOQOL-items (Geyh, 2010)

# Employment rate (18-65 yrs)

	Switzerland	Denmark	Netherlands	Norway
Pre-SCI				
Empl.+Educ. (%)	84	89	88	88
Post-SCI				
Empl.+Educ. (%)	58	55	53	54
Empl. (%)	55	54	52	52
Empl. hours* pre	39	39	37	39
post	23	26	26	27

\* Participants employed pre-SCI and post-SCI, respectively



# Those unemployed (18-65yrs)

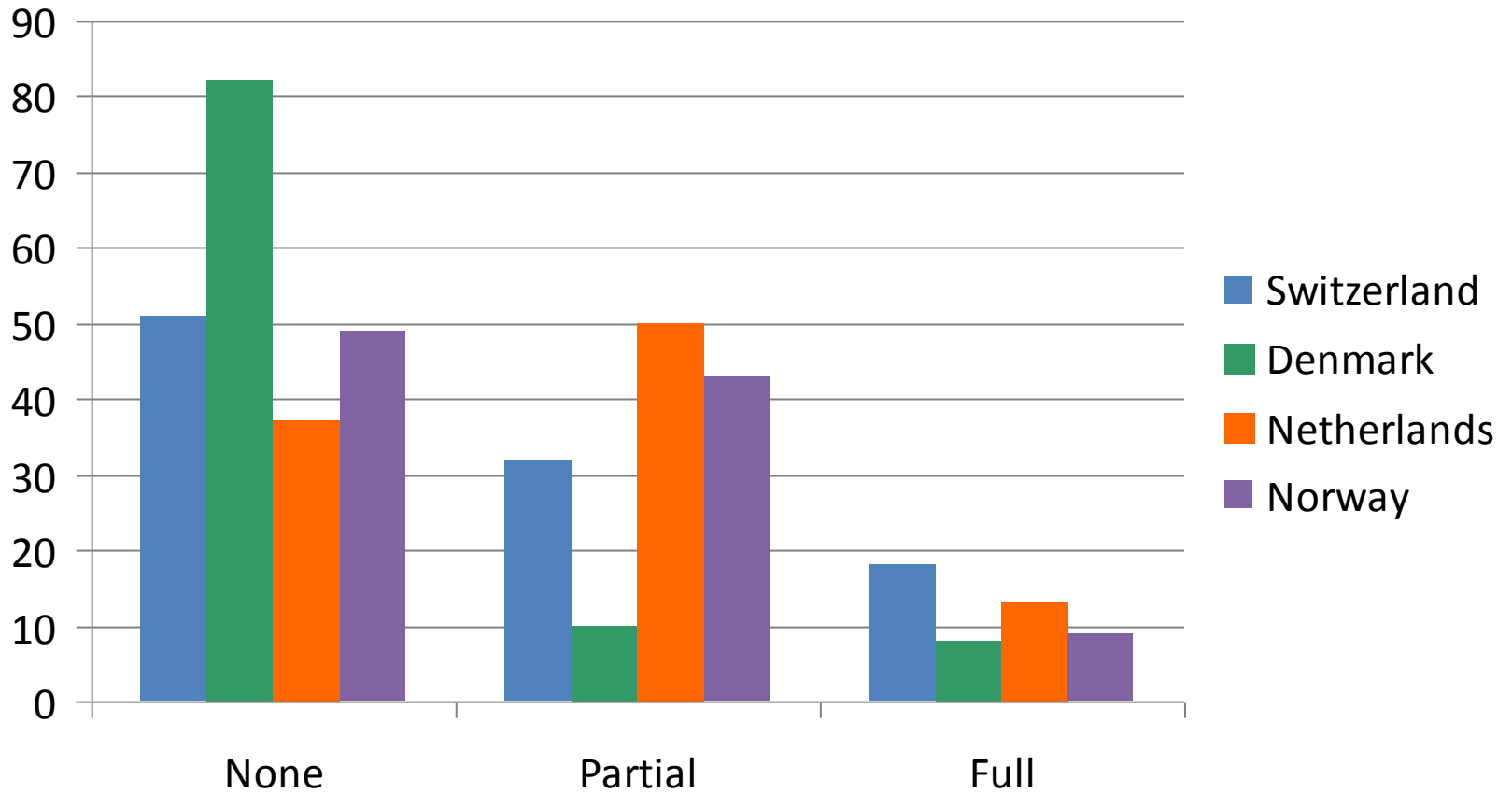
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	Switzerland	Denmark	Netherlands	Norway
Having the desire to work	53	55	57	54
Feeling able to work	60	65	58	71

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\* Participants employed pre-SCI and post-SCI, respectively

# Disability pension



# Factors related to employment

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	<b>Bi-variate</b>	<b>Multivariate (all countries)</b>
Age	NL	X
Male gender	CH, NL	-
Education	CH, NL, NO	X
Type of SCI	DK	
Time since SCI	NL	
Independence in ADL	CH, NL, NO	X
Secondary health conditions	NL, NO	X
Country	-	-

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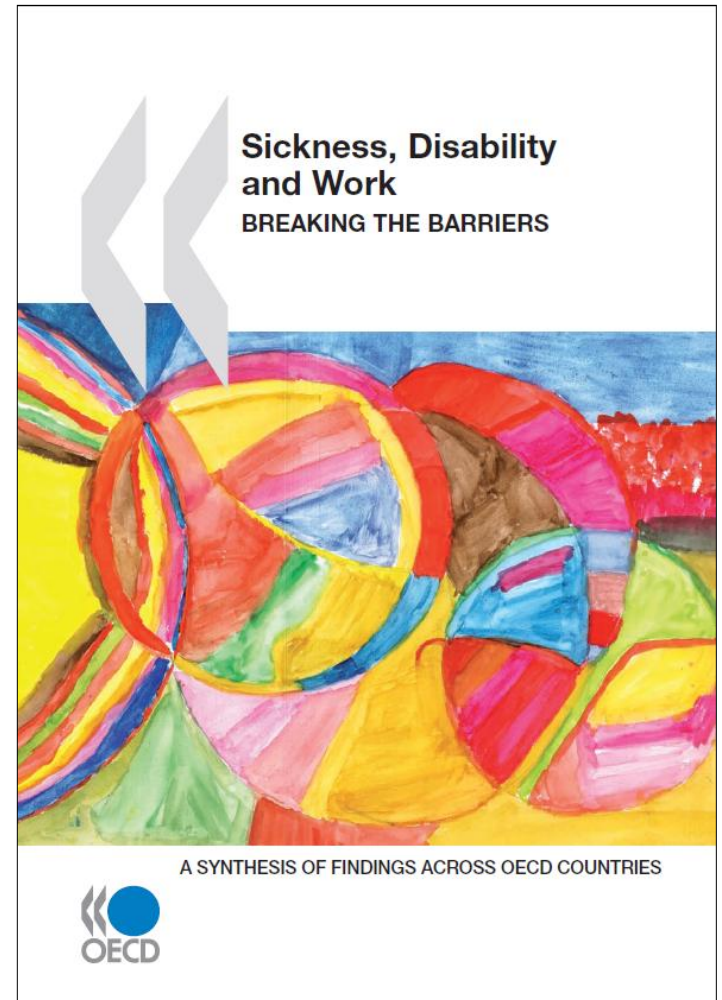
# Conclusions

- Employment rates
  - Go down after SCI.
  - Are high in this study compared to other studies.
  - Much part-time work
  - Combination of employment and disability pension
  - Hardly any differences between countries.
- Significant associations with functional independence and secondary health conditions
- Need to extend ILIAS to other countries
  - Australia, Malaysia,.....?

# Enhancing employment (OECD 2010)

- Disability benefits should be a single component of a larger “participation package”. Adapted to individual needs and capacities and designed primarily to return people to work.

OECD, 2010



# System factors

- Vocational rehabilitation programs
- Workplace support programs (adaptations, support at the workplace)
- Legislation, e.g., quota
- Disability benefits/"trap" (Tate 1994; Pflaum et al, 2009)
- General employment rate (Pflaum 2006)
- Area of living (SES urbanization) (Botticello 2012)

# Income protection in NL

- Compulsory insurance
- 2 year job guarantee
  - Income 1<sup>th</sup> yr 100% 2<sup>nd</sup> yr 70%
- Disability pension
  - if >35% loss of earning capacity (of last earned income)
  - 35-80% or >80% temporary
  - > 80% permanent: 75% of last income (up to € 50,000)
- Combination of income and disability benefits is possible

# Employer protection in NL

- Bonus € 7000/year for 3 years
- 2-6 months unpaid trial period
- No-risk insurance 70% of income during 5 year or longer
- Income compensation for 2 years.
- Special arrangements for individuals disabled at young age
- Reimbursement of reintegration costs



# Conclusions

- We need more figures on the employment situation of individuals with SCI in Europe and worldwide
- Employment rates in SCI populations need to go up
- Most important measures to be taken seem:
  - Vocational training and employment support
  - Overcoming misconceptions/discrimination of people with SCI
  - Workplace accommodations
  - Securing economic self-sufficiency

# Thank you for your attention

