



"Ratto d'Europa", 1639 – 1640 Guido Reni, London National Gallery

***"The impact of the crisis
on persons with
Spinal Cord Injury:
a comparison among
European countries"***

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Lucignano, 23-05-2012

ISTUD FOUNDATION



ISTUD Foundation is an independent business school that operates in Europe in the field of executive education, advanced lifelong learning and in the field of management research. As independent advanced centre of management research and training.

ISTUD has been the first Italian Business School to be associated to EFMD European Foundation for Management Development and it has always played an active part in its activities

Its mission is to consolidate and spread a management culture based on corporate social responsibility, multiculturalism, professional upright and value production.



HEALTH CARE AND WELLBEING AREA

Health and Healthcare conceives, designs and implements activities of organizational research and training for the development of individual professionals, whole teams or even their entire organizations. All this is aimed at advancing a healthcare system fully capable of responding to the patients' real needs and to their frame of reference. The ultimate goal is to achieve a workable balance between effective therapies and the efficiency of healthcare structures.

This practice offers the **healthcare sector** its multidisciplinary competencies of **training**, **organizational research** and consulting.



Our research about Spinal Cord Injury



The ALMA Project (Harmonization of treatments for spinal cord injury) had a very high ambition in the social and health care context, where no uniform functional and organizational models exist for the treatment of people with Spinal Cord Injury in Italy. The group worked efficiently and every person involved satisfied the relevant roles, competences, and responsibilities, working together towards the growth of professionals and providers and to give voice to people with Spinal Cord Injury”.



The composition of the social and health care offer for people with Spinal Cord Injury: census of the centres, professions and assistance services in Italy.

Mapping of the pathway for people with Spinal Cord Injury in Italy;



Needs and costs of people with spinal cord injury, tangible and intangible assets for people with Spinal Cord Injury and their families;

ANTARES (Analysis of Not Traumatic Spinal Cord Injury - assistance, rules, team, statistics);



Objective

To analyse the impact of the economic crisis on rehabilitation pathways and life of persons with Spinal Cord Injury (SCI) in 10 European countries:

France, Germany, Ireland, Italy, Norway, Slovenia, Spain, Switzerland, The Netherlands, UK



The research pursued the objective to contribute to increase awareness among countries on the needs of persons with this Spinal Cord Injury, as well as to create a global European culture for their services improvement, which is able to counteract the dramatic current shortage of resources in this continent.

Methodology

- Setting up of a **committee** composed by representative members experienced in Spinal Cord Injury able to define the most important items to investigate
- **Desk research:** to collect National and European bibliography on the social context and the organization of the pathway and services for people with Spinal Cord Injury in the different Countries
- **Field research:** to obtain quantitative and qualitative information

Two instruments: QUESTIONNAIRE for the associations /
INTERVIEW to associations and Spinal cord unit

- with National Association for person with SCI

- Main  European Spinal Cord Injury Federation



Acknowledgments

ASSOCIATIONS

- *Spinal Injuries Ireland*
- *Italian Federation of Paraplegics and Tetraplegics Associations*
 - *Dutch Spinal Cord Injury Association*
 - *Norwegian Spinal Cord Injuries Association*
 - *Paraplegics Association of Slovenia*
 - *Spanish Association of Spinal Cord Injury*
 - *Swiss Paraplegic Association*
 - *The UK Spinal Injuries Association*

Acknowledgments

SCI Units

- **Spinal Cord Injury Unit , Klinik Bayreuth - Germany**
- **National Rehabilitation Hospital, Dublin - Ireland**
- **Rehabilitation Centre de Hoogstraat, Utrecht –The Netherlands**
- **Sunnaas Rehabilitation Hospital, Oslo – Norway**
- **Swiss Paraplegic Centre, Nottwil – Switzerland**

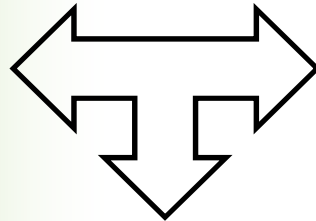


Visits at the Sunnaas Rehabilitation Hospital in Oslo and the Rehabilitation Centre de Hoogstraat in Utrecht

Desk research: *focusing on...*

Policies for disabled people

- Social protection
- Healthcare services
- Employment
- Accessibility and mobility
- Social inclusion



Spinal Cord Injury

- Rehabilitation centres
- Rehabilitation services
- Provision of aids
- Social cost
- Organizations

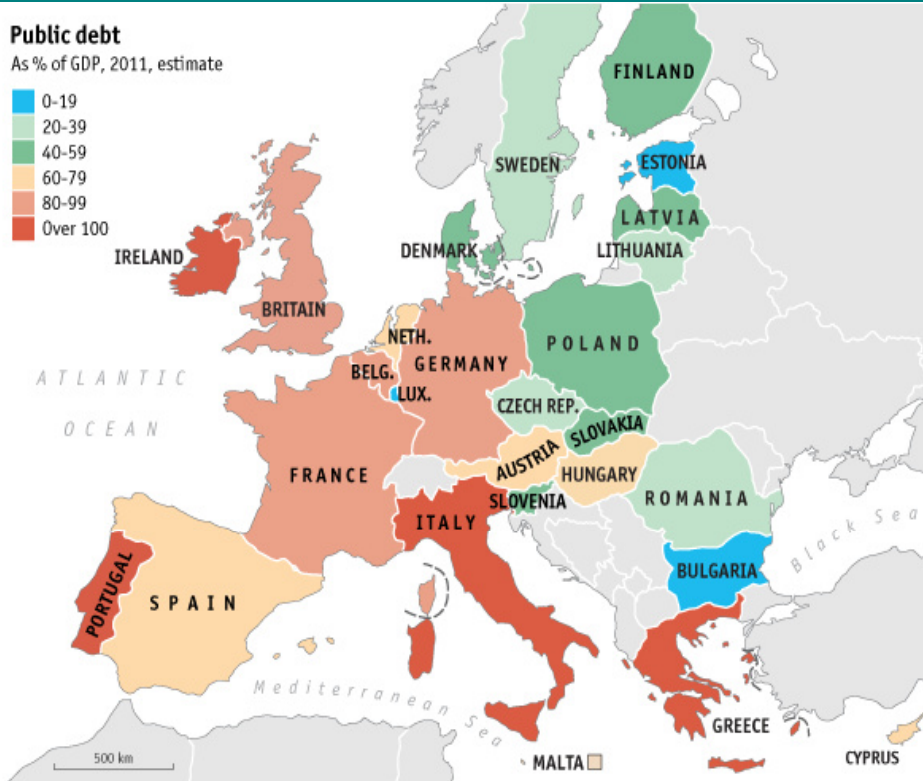
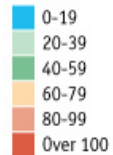
Economic crisis

- Economic context for disability policy
 - Recent budget cuts
 - Social impact

Desk research: the economic crisis

Public debt

As % of GDP, 2011, estimate



SOURCE: THE ECONOMIST

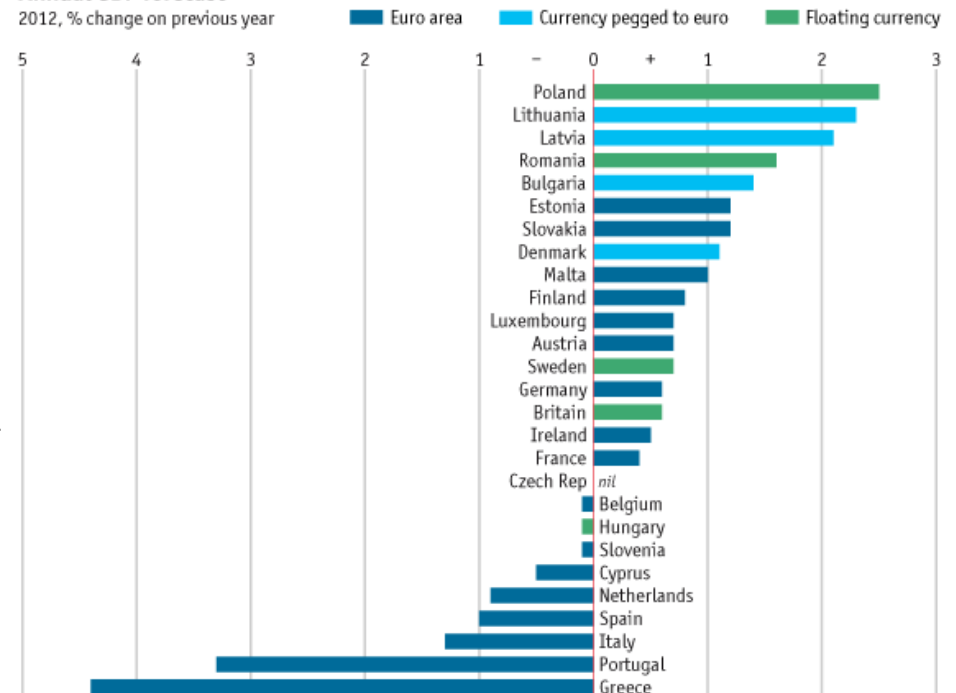
How European countries are facing the economic crisis?

Which are the most affected countries?

Two different speeds?

Annual GDP forecast

2012, % change on previous year



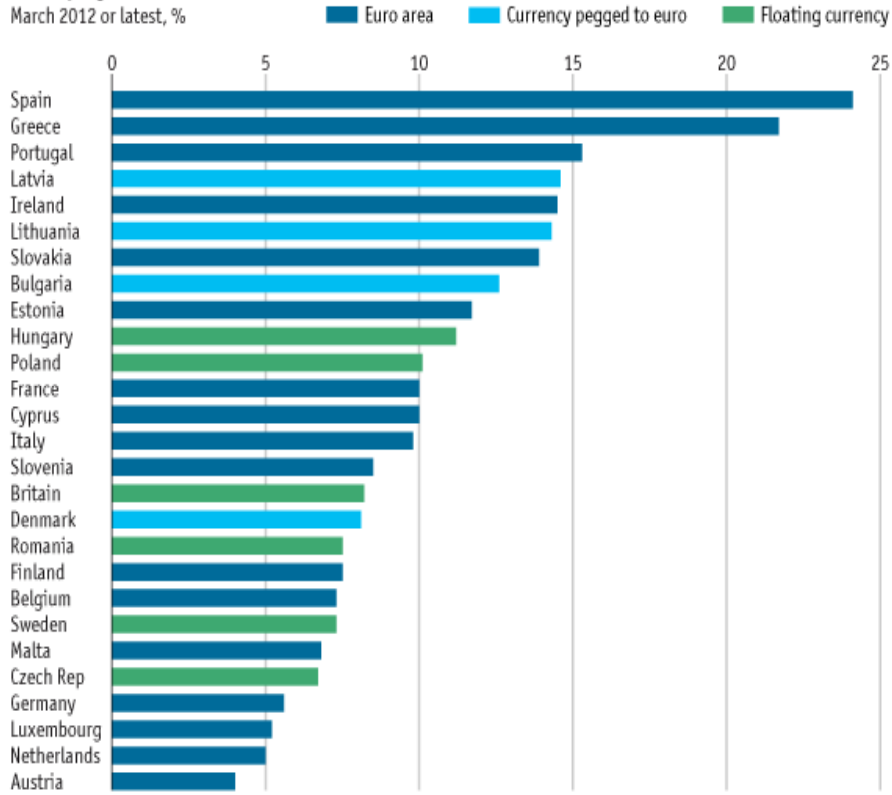
Which are the consequences on the welfare policies?

Which are the trends?

Europe's Economies: unemployment rate

Unemployment rate

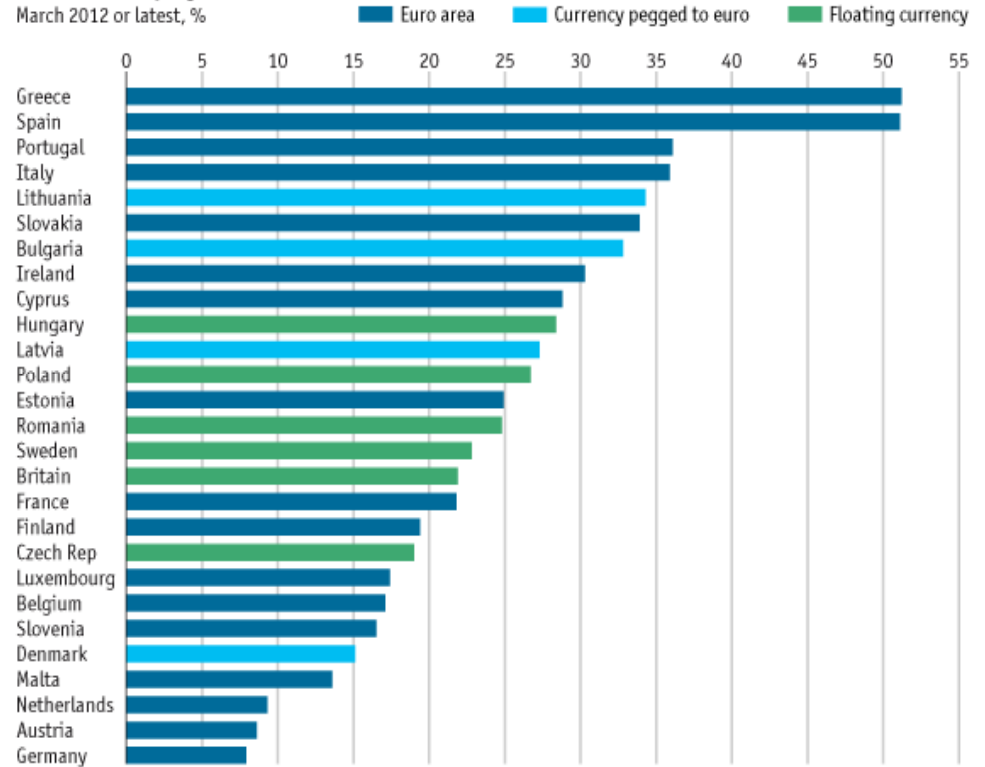
March 2012 or latest, %



SOURCE: THE ECONOMIST

Youth* unemployment rate

March 2012 or latest, %



SOURCE: THE ECONOMIST

Regression results

Regression results: impact of a 1 percentage point increase in the output gap on employment levels in general and the additional disadvantage for people with disability, percentages

	Employment effect	
	Men	Women
Effect of having a disability	-19.03 (0.000)***	-11.94 (0.000)***
Overall impact of the output gap change on people with disability	-1.12	-2.01
<i>Of which:</i>		
<i>Impact of output gap change on all individuals</i>	-0.72 (0.000)***	-1.15 (0.000)***
<i>Additional impact of the output gap change on those with disability</i>	-0.39 (0.001)***	-0.86 (0.000)***

*** Significant at 1% level. The output gap is the percentage difference between potential and actual output.

Source: OECD calculations based on ECHP 1994-2001.

Desk research: “disability”, a not uniform concept

	Population	Disabled people	%
France	64.876.618	6.000.000	10%
Germany	81.702.329	8.800.000	10.6%
Ireland	4.581.269	393.800	9%
Italy	60.776.531	2.600.000	5%
The Netherlands	16.783.092	1.700.000	10%
Norway	4.883.111	1.220.777	25%
Slovenia	2.054.741	115.000	6%
Spain	46.076.989	4.500.000	10%
Switzerland	7.785.800	750.000	10%
UK	61.827.200	10.000.000	16%

Percentages of disability vary between 5% in Italy, 16% in UK, up to 25% in Norway

Desk research: different healthcare and welfare models

Nordic model: **universal welfare provision**, based on the values of equal opportunities, social solidarity and security for all. Everyone is entitled to equal access to social and health services.

Continental model: **social insurance model**, benefits are primarily earned through employment and the level of income security depends on the size of the wage.

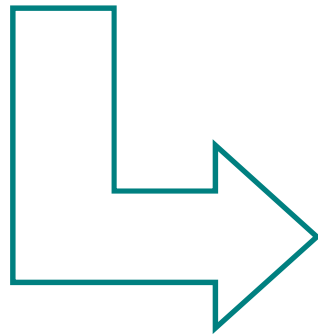
Anglosaxon model: based on welfare assistance. It **attempts to promote labour market providing incentives to work** and limiting the other general benefits.

Mediterranean model: **The universal welfare provision** consists in workers paying contributions toward their future benefits.

Desk research: SCI in Europe

What we know :

- About 333.000 persons with SCI
- 11.000 new cases/year
- Most frequent causes: road and sport accidents
- Average age: 33 years



But SCI person's profile is changing :

- Non traumatic SCI are increasing
- Ageing of SCI population

The questionnaire

In an electronic format, sent by email to the 10 National Organizations for people with Spinal Cord Injury, to obtain data about:

- 1) General disability and Spinal Cord Injury data
- 2) Rehabilitation services expenditure and recent budget cuts
- 3) Welfare expenditure and supports
- 4) Aids provision
- 5) Employment
- 6) Discrimination and social inclusion
- 7) Representative Organization

**Redemption
80%**

The questionnaire: SCI numbers

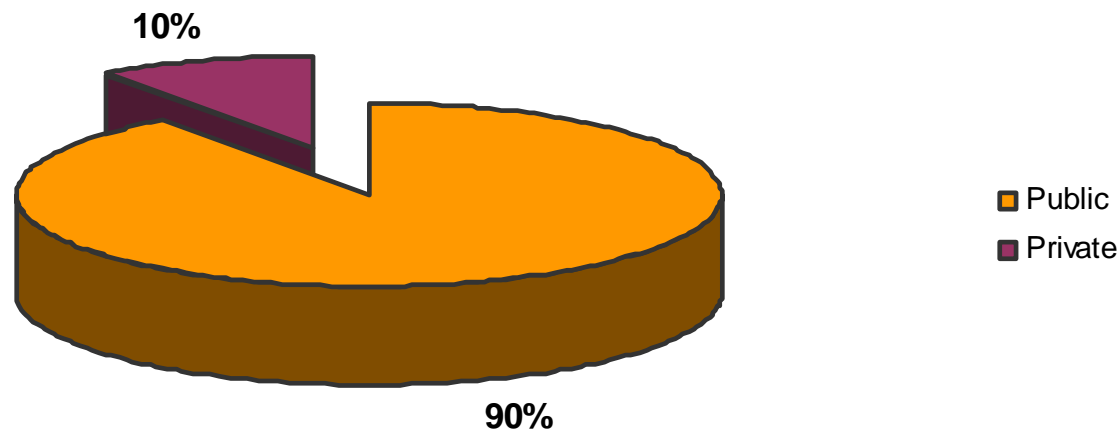
	Total SCI 2011	New SCI/ year	SCI Units	Total SCI 2011/ SCI Units	SCI reference population
Ireland	1500	50	1	1.500	4.581.269
Italy	80000	2000	23*	3.478	2.642.457
Netherlands	15000	200	8	1.875	2.097.887
Norway	4500	120	3	1.500	1.627.704
Slovenia	1080	35	1	1.080	2.054.741
Spain	30000	1000	10	3.000	4.607.699
Switzerland	4500	250	4	1.125	1.946.450
UK	40000	1000	11	3.636	5.620.655

Italy, UK and Spain: the highest incidence of SCI

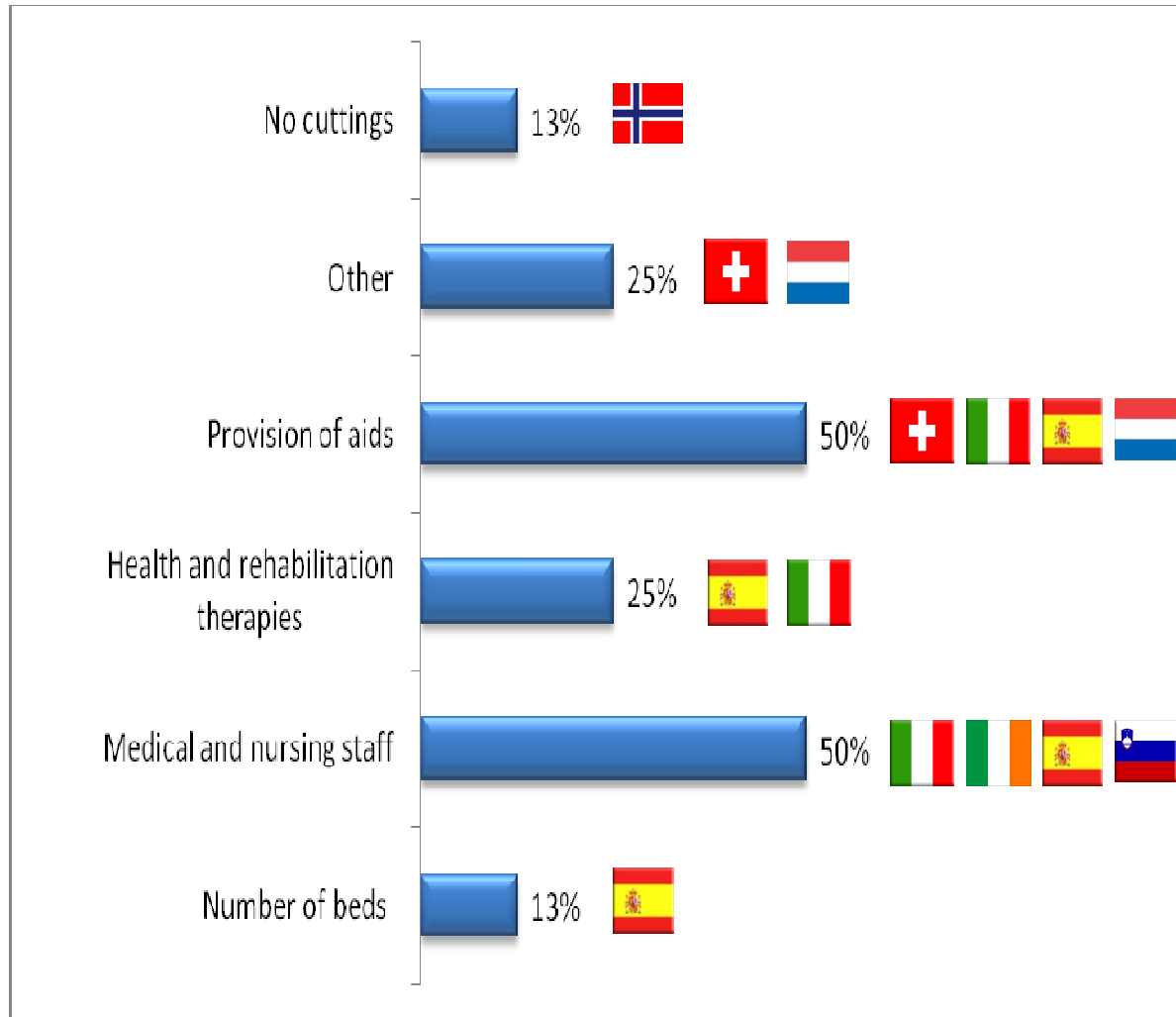
*: 8 USU + 15 SCI Units

The questionnaire: SCI entrusted to public service

SCI profile

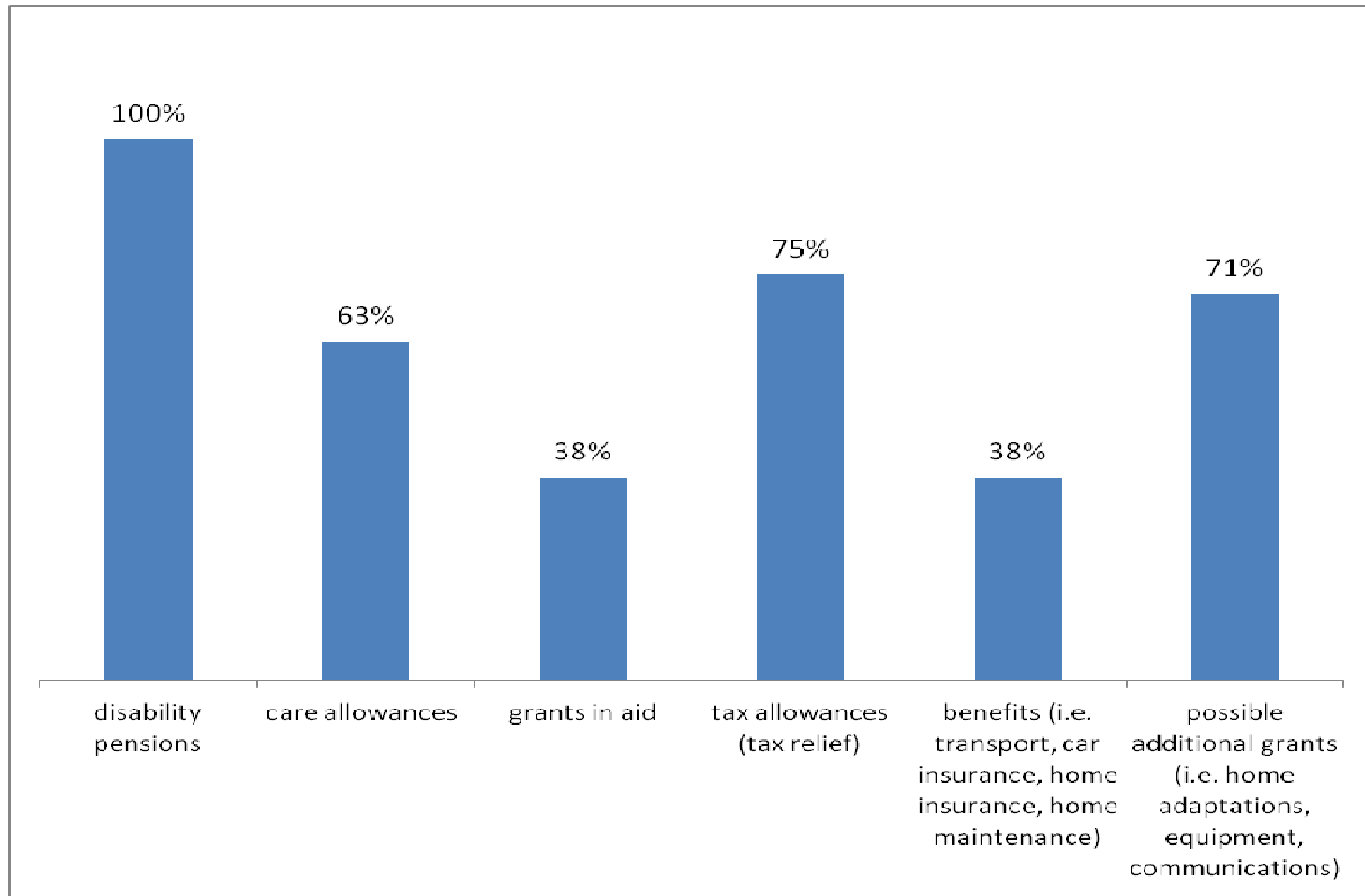


The questionnaire: budget cuts



Reductions are particularly felt in Spain and Italy

Which income supports? disability pension is the universal support



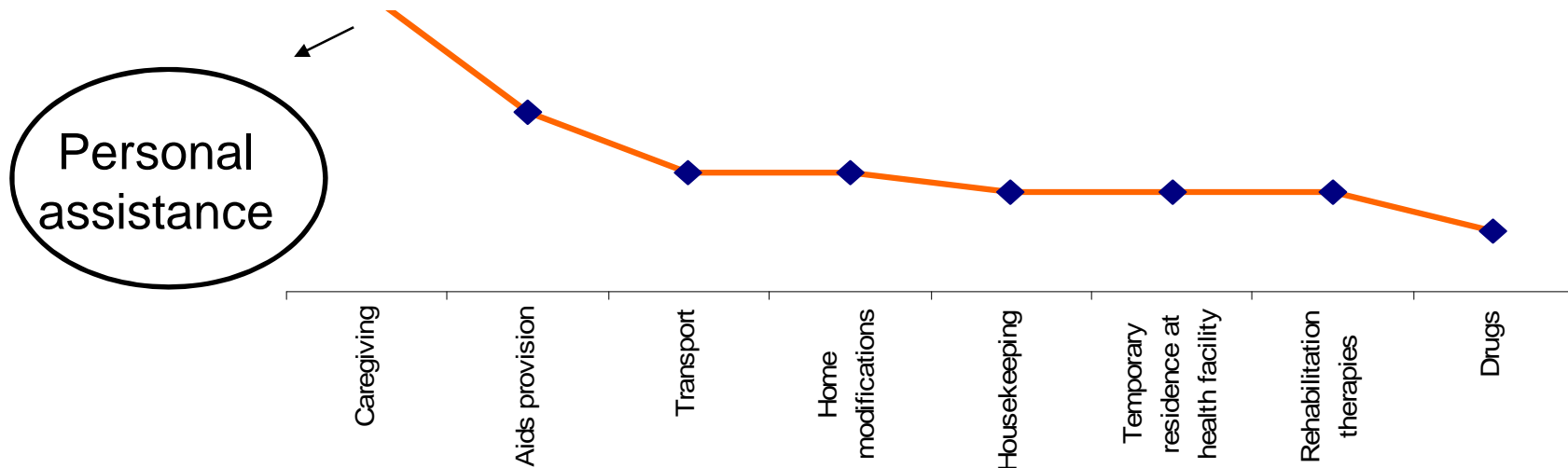
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The questionnaire: extra-costs for families

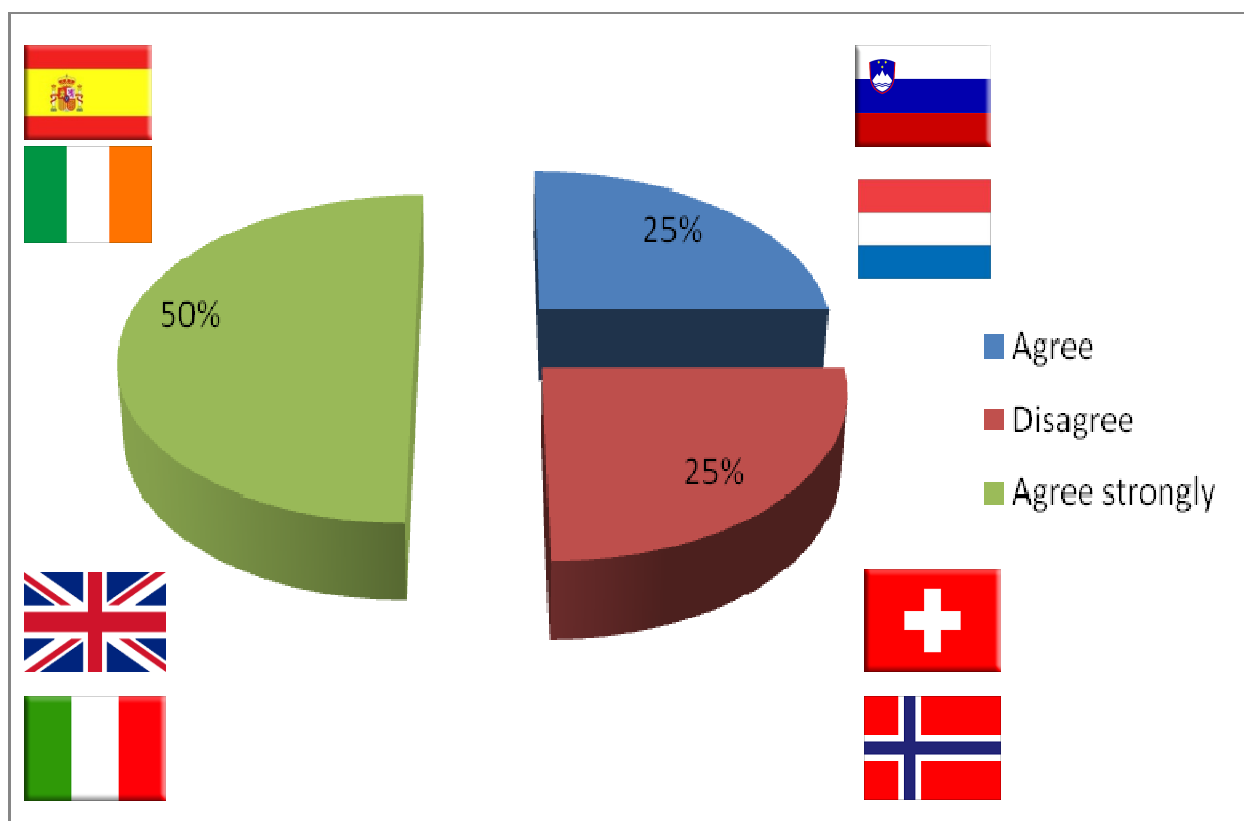
- ✓ Caregiving
- ✓ Aids provision
- ✓ Transport
- ✓ Drugs

- ✓ Home modifications
- ✓ Housekeeping
- ✓ Rehabilit
- ✓ Temporary residence at health facility



The questionnaire: deterioration of aids provision

Compared to 5 years ago, it is more difficult for a person with Spinal Cord Injury to obtain all the necessary technological devices and services:



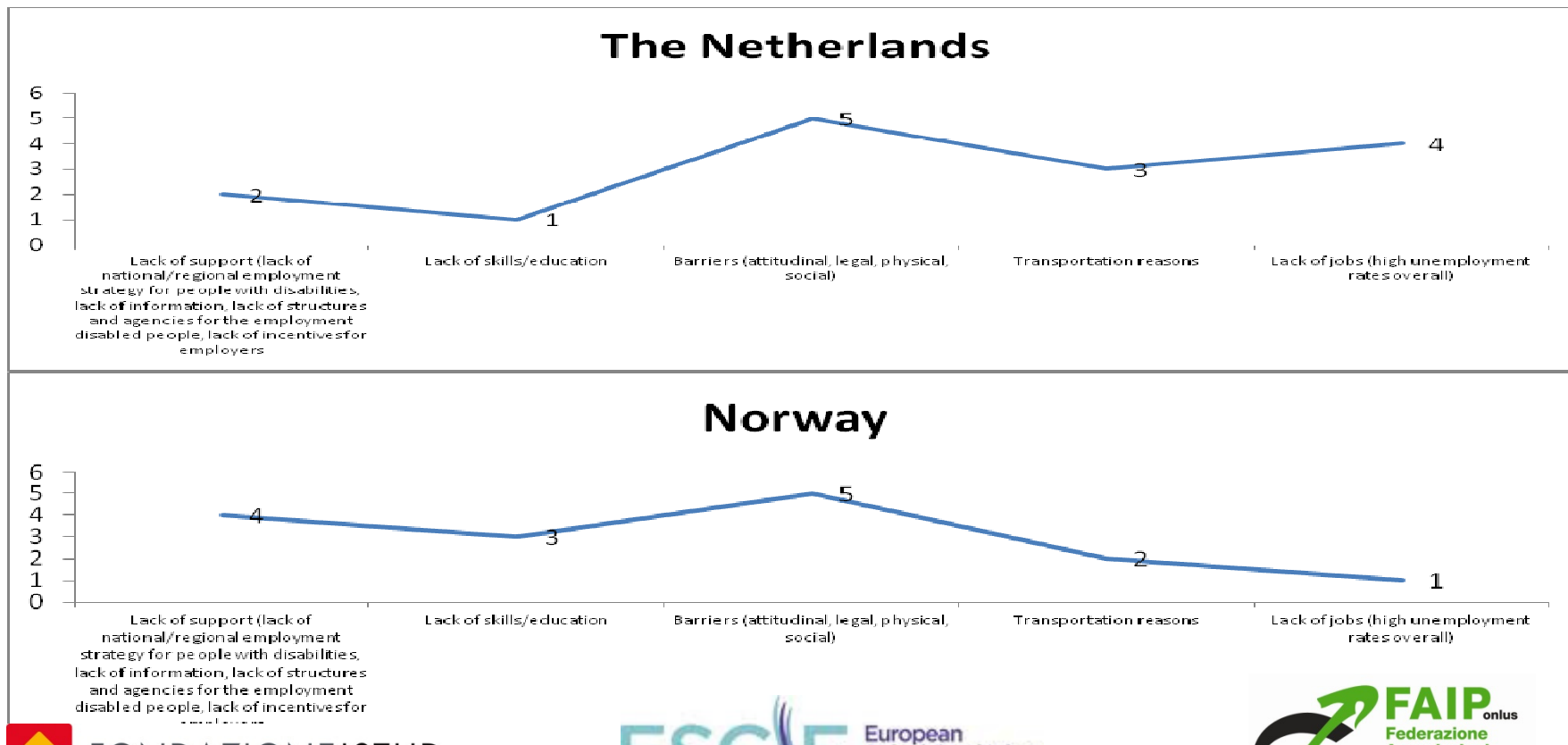
6 Countries reporting lower quality standard

	Higher quality standard	The same quality standard	Lower quality standard	Don't Know
Wheelchairs		Netherlands, Switzerland, UK, Ireland, Spain, Norway,	Slovenia, Italy	
Special beds		Netherlands, Switzerland, UK, Ireland, Spain, Norway, Italy, Slovenia		
Mattress		Netherlands, Switzerland, UK, Ireland, Slovenia, Norway,	Spain, Italy	
Cushion		Netherlands, Switzerland, UK, Ireland, Spain, Norway, Italy	Slovenia	
Shower chair		Netherlands, Switzerland, Ireland, Spain, Norway,	UK, Slovenia, Italy	
Catheter		Netherlands, UK, Ireland, Spain, Norway, Italy, Slovenia	Switzerland	
Hygienic aids		Netherlands, Ireland, Norway, Slovenia	Switzerland, UK, Spain, Italy	
Hoist manual		Netherlands, Switzerland, Ireland, Norway	Slovenia, Spain, Italy	UK
Hoist electric		Netherlands, Switzerland, Ireland, Norway	Slovenia, Spain, Italy	UK
Home modification		Netherlands, UK, Ireland, Spain, Norway, Italy	UK, Spain, Italy	Slovenia
Adapted vehicle		UK, Ireland, Spain, Norway, Italy	Netherlands, Spain	Slovenia

The questionnaire: barriers to employment

Reasons why persons with SCI cannot be included in the labor market:

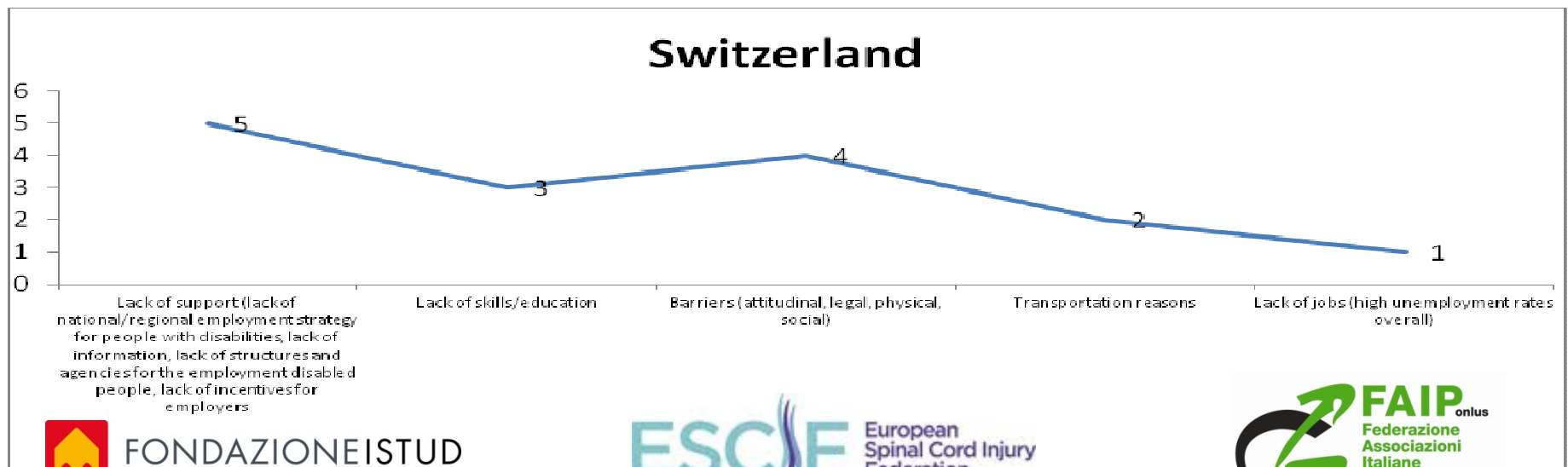
1. Lack of support in the entering the labor market
2. Barriers, physical and attitudinal
3. Lack of job opportunities



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The questionnaire: barriers to employment



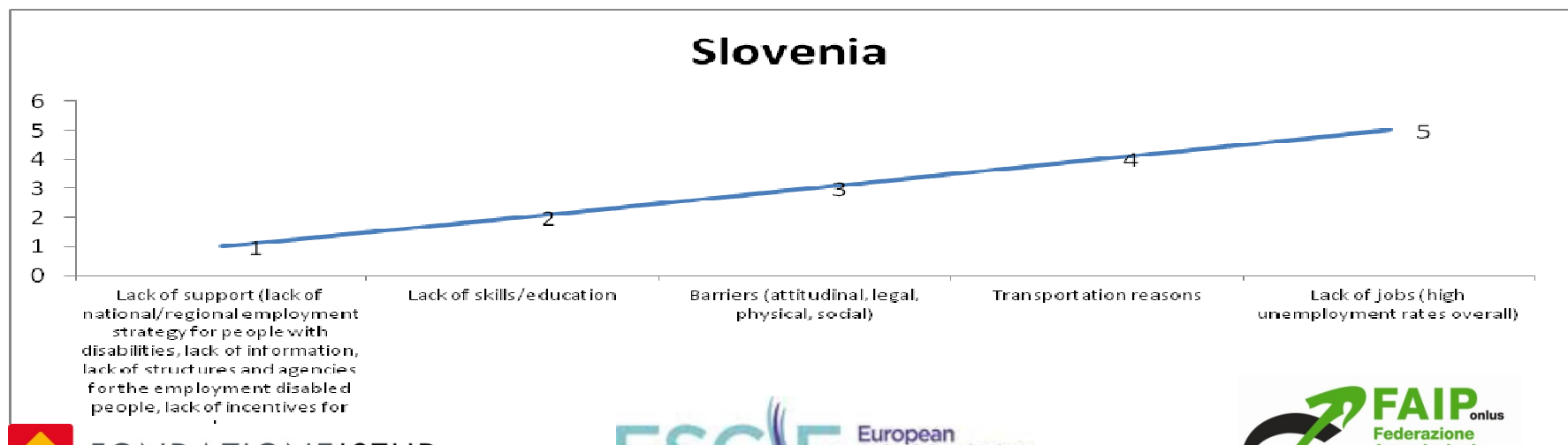
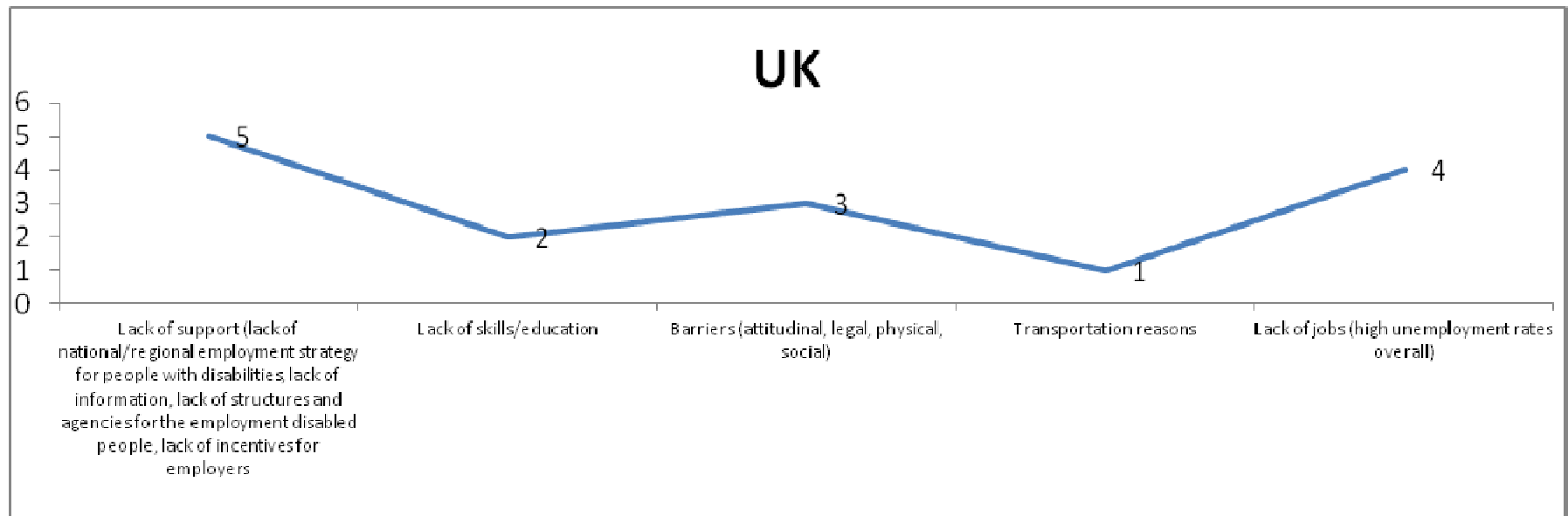
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European
Spinal Cord Injury
Federation



The questionnaire: barriers to employment

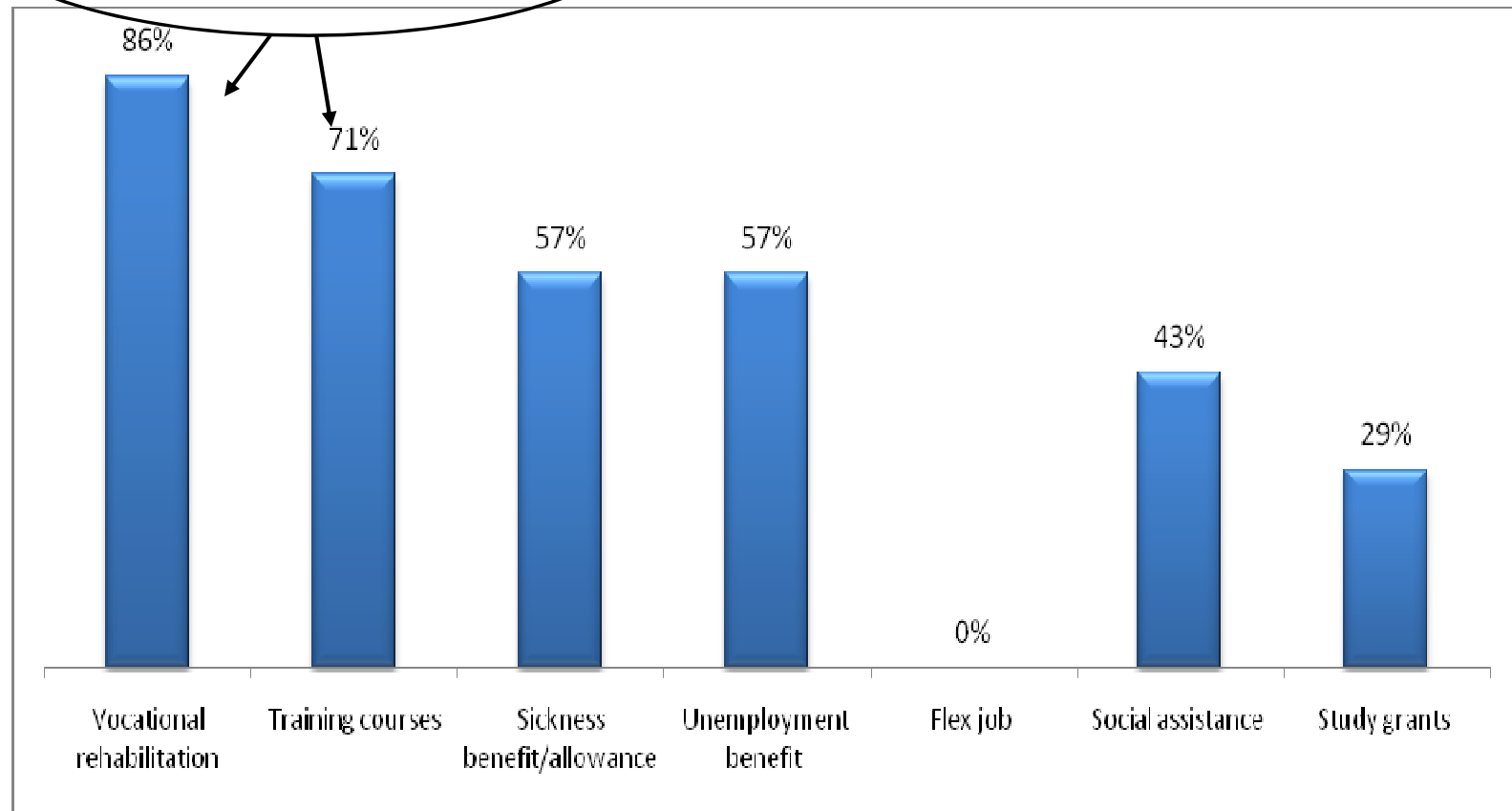


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Which are the supports for the employment? the importance of vocational rehabilitation

Part of rehabilitation
pathway



The questionnaire: What is it considered a discrimination?

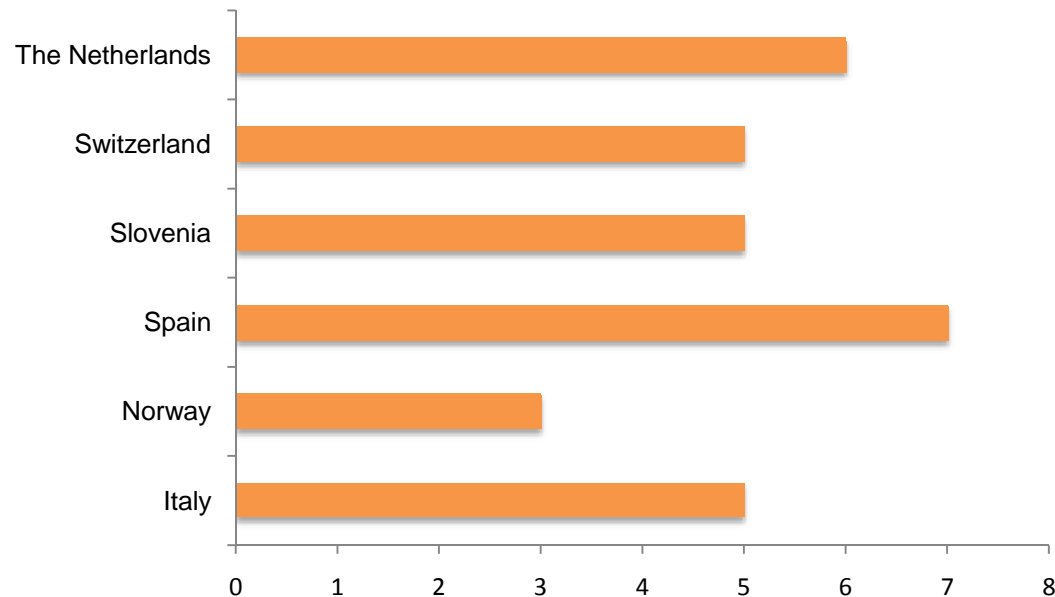
The number of discriminating episodes are considered by Associations **constant or diminished**, but:

“the real discrimination for people with Spinal Cord Injury is not being able to reach a building; if you can’t go to the cinema, or theater, you are discriminated”

Physical barriers
are the most frequent cause of discrimination

level of social inclusion: 0 no gap, 10 max gap

Difference in terms of social inclusion between people with disabilities and without disabilities (on a scale from 1 to 10):



Many steps have been made in the last years, many others have to be carried out to obtain a real social inclusion of persons with disabilities

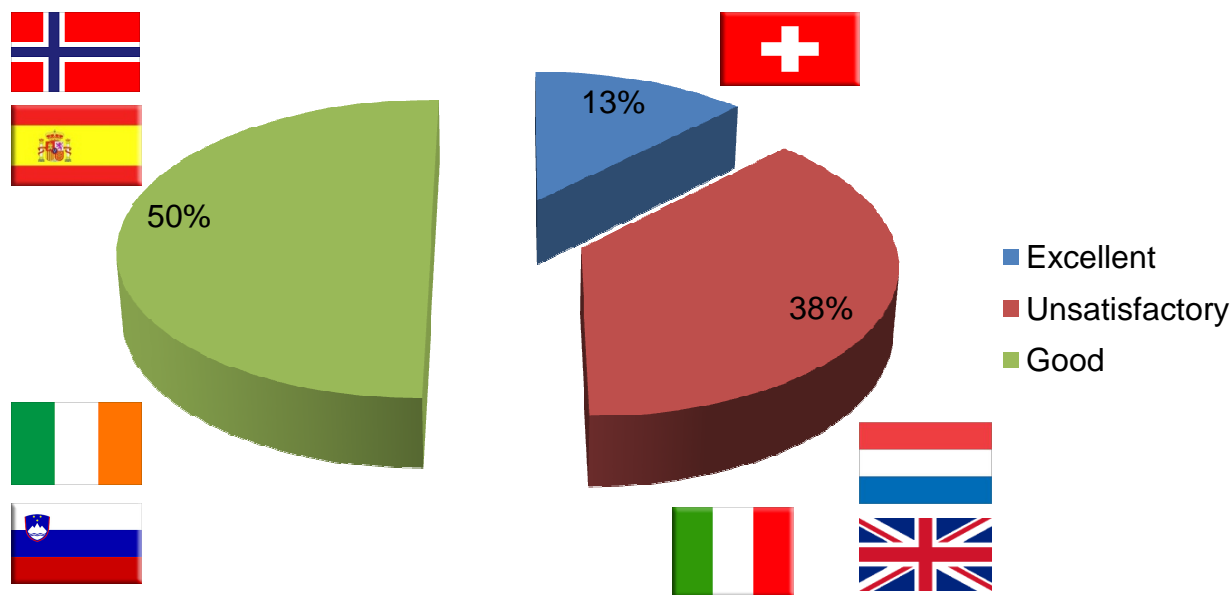
The questionnaire: Associations' priorities

Employment
Poverty risk
Communities based services



priority issues for the social
inclusion of persons with SCI

Relations with governments:



The questionnaire: hypothesis of budget funding

Ratio between the budget of Associations in 2011 and the number of persons with SCI in the respective countries:

Country	Association's budget/ Total SCI persons
The Netherlands	40 €
Switzerland	1850 €
UK	62 €
Slovenia	1907 €
Spain	46 €
Norway	146 €

The highest amounts

Linked to assistance activities?

Funding at disposal for each person for Association services provision

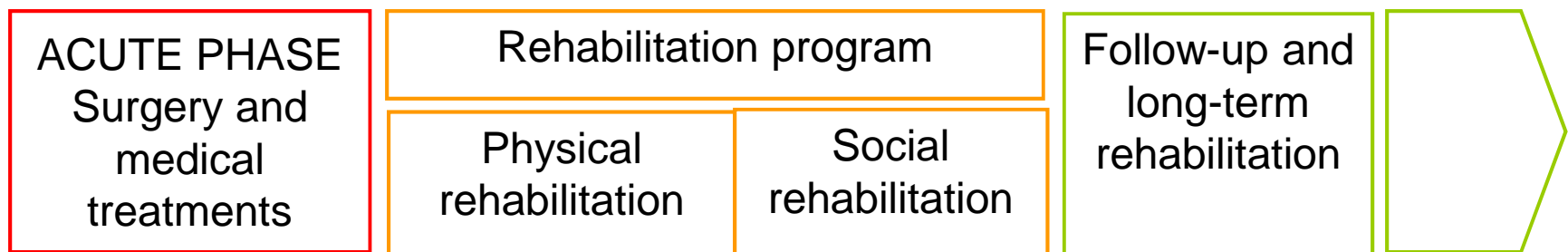
Interviews to SCI Units referents

Carried out in presence, by phone or by Skype connection,
to obtain information about:

- SCI pathway management
- SCI care program
- National network
- Statistics
- Centres management
- Budget and costs
- Critical situations
- Projects

Uniform care routing...until the discharge

Rehabilitation pathways are essentially uniform among the SCI Units



interdisciplinary treatments

interdisciplinary team

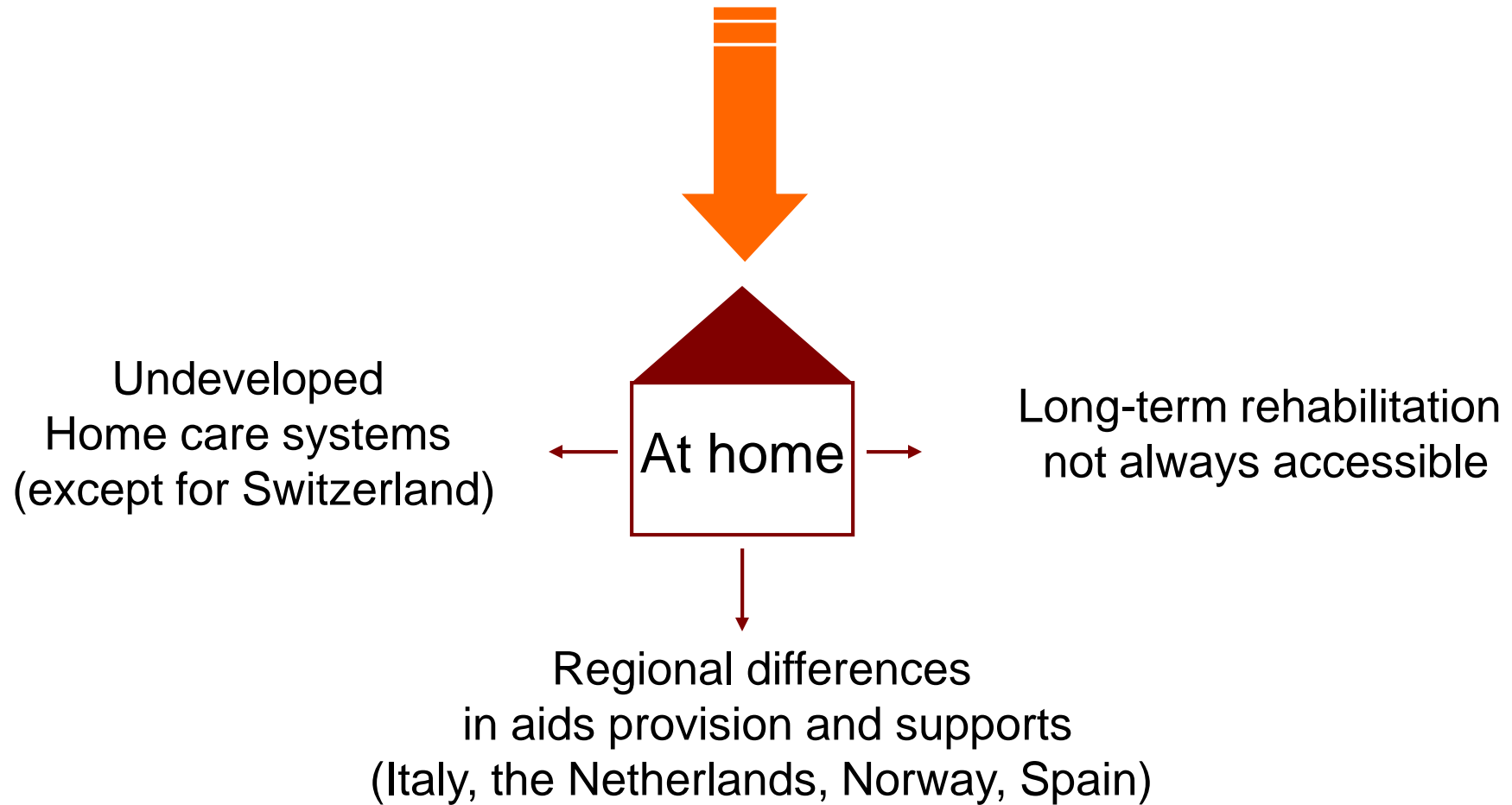


home



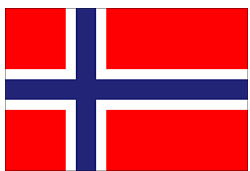
?

And after the discharge?



Are the SCI Units and beds sufficient for the requirements of the country?

Yes:



Yes but more beds are necessary:



No:



Statistics on SCI from the interviews

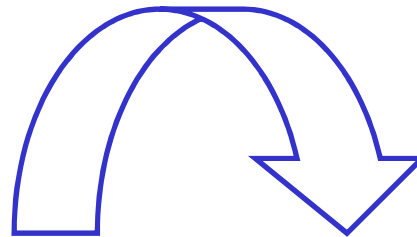
Mean Statistics limited to 5 SCI Centers: *NRH Dublin, Sunnaas Rehabilitation Hospital Oslo, Rehabilitation Centre de Hoogstraat Utrecht, Klinik Bayreuth, Swiss Paraplegic Centre Nottwil*

Traumatic SCI: 44%

Paraplegia: 55%

Male: 68%

Average age: 47,5 years



✓ **Non traumatic SCI** more than 50%

✓ **Ageing of persons with SCI** (*EU average: 33 years*)

Re-admissions: 50%

Generally, percentage of re-admission is unknown, but it is estimated *almost 50%*

The most frequent complications:

- ✓ Pressure sores
- ✓ Urinary tract infections
- ✓ Bowel and bladder disfunctions
- ✓ Pulmonary complications

A *waiting list* is used for re-admissions, except for the emergency cases

Shorter length of stay?

Average length of stay:

Paraplegia:
122 days (4 months)

Tetraplegia:
197 days (6,5 months)

A trend to reduce the length of stay in the SCI Units is reported in Norway, Germany, UK and Switzerland. Intermediate centre which complete the rehabilitation program. To better reallocate resources and reduce costs

Does this efficient management correspond to an equal effectiveness provided by the SCI care?

Network

- Network among SCI Units: yes
- Network among SCI Units and local hospitals/centres: yes
- *Network among SCI Units and health local districts: not always (difficult in Ireland, Italy, Norway)*
- International network: massive for scientific societies, and present for associations but to empower
National Register of Spinal Cord Injury:
 - Italy: **no**
 - The Netherlands: **no**
 - Norway: **since 2011, managed by SCI Units**
 - Spain: **no**
 - Switzerland: **in preparation since 2009, managed by Swiss Paraplegic Foundation**
 - UK: **no**

Budget cuts: where?



Ireland:

6% budget reduction at NRH
Further 4% reduction expected

→ Reduction in beds and
worker staff



Italy:

budget reductions for SCI Units

→ Some SCI Units at risk to
be closed
→ Reduction in worker staff
Reduction in length of stay
at SCI Units



Spain:

reduction in
rehabilitation services

→ Reduction in beds and
worker staff
→ Reduction in length of
stay at SCI Units

“2012 will be the year with more cuts in social services and protection for people with disabilities.”

Budget cuts: where?

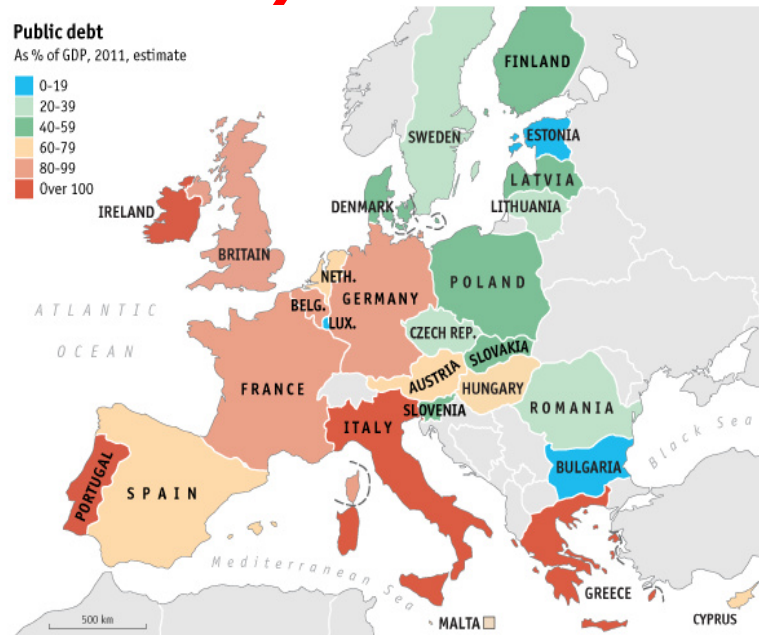
Strong reductions

Italy
Spain
Ireland

First alarm bells

The Netherlands
UK
Slovenia

No
current cut
Germany
Norway
Switzerland



*Different European settings
or different healthcare
and welfare systems?*

The importance of social reintegration

In each SCI Units:

- ✓ Vocational rehabilitation, training courses
- ✓ Sporting activities
- ✓ Laboratories and socializing areas



Associations in the SCI Units

Associations are very closed to SCI Units:

- ✓ Vocational rehabilitation
- ✓ Socializing, sporting and educational activities
- ✓ peer support
- ✓ information
- ✓ fund raising
- ✓ research and prevention projects.

What are the most critical situations for persons with SCI?

Two different priorities:



Care program

Italy: *“we need more SCI Units, beds and more resources to guarantee an high-grade care to persons with SCI”*

Slovenia: *“the reimbursement system has still to be structured, now persons pay many extra-costs”*

Spain: *“the recent budget cuts are worrying, the rehabilitation pathway will be worsen for persons with SCI”*



Social inclusion

Ireland: *“it is still to work on general education of population, who don't know SCI”*

The Netherlands: *“the main problem are accessibility and transport, which cause discrimination”*

Norway: *“persons with SCI have to face expensive living cost”*

Switzerland: *“the lack of sensitization and education cause still many barriers”*

UK: *“persons need stronger support to improve their skill and entering the market labor”*

Future projects for people with Spinal Cord Injury

To maintain the current situation:

Germany
The Netherlands

To continue to fight for more
resources:
Italy

National guidelines for SCI care and
Long-term treatments:
Ireland

To enhance diffusion capillarity of
the activities:
Ireland

To build a new structure
for Rehabilitations:
Norway
Slovenia

To establish a National Register:
Switzerland

To avoid Europe to be raped



An European Observatory for SCI?

PLANNING an active an European Observatory for Spinal Cord Injury on policies, statistics and needs and exchange of best practices and of solidarity among countries.