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

Maria Giulia Marini

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

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 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.
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);
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 contest 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
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

How European countries are facing the economic crisis?

Which are the most affected countries?

Two different speeds?

Which are the consequences on the welfare policies?

Which are the trends?
Europe’s Economies: unemployment rate

**Unemployment rate**
March 2012 or latest, %

- Spain
- Greece
- Portugal
- Latvia
- Ireland
- Lithuania
- Slovakia
- Bulgaria
- Estonia
- Hungary
- Poland
- France
- Cyprus
- Italy
- Slovenia
- Britain
- Denmark
- Romania
- Finland
- Belgium
- Sweden
- Malta
- Czech Rep
- Germany
- Luxembourg
- Netherlands
- Austria

**Youth* unemployment rate**
March 2012 or latest, %

- Greece
- Spain
- Portugal
- Italy
- Lithuania
- Slovakia
- Bulgaria
- Ireland
- Cyprus
- Hungary
- Latvia
- Poland
- Estonia
- Romania
- Sweden
- Britain
- France
- Finland
- Czech Rep
- Luxembourg
- Belgium
- Slovenia
- Denmark
- Malta
- Netherlands
- Austria
- Germany

* SOURCE: THE ECONOMIST
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

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

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

Desk research:  
“disability”, a not uniform concept

<table>
<thead>
<tr>
<th>Country</th>
<th>Population</th>
<th>Disabled people</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>France</td>
<td>64,876,618</td>
<td>6,000,000</td>
<td>10%</td>
</tr>
<tr>
<td>Germany</td>
<td>81,702,329</td>
<td>8,800,000</td>
<td>10.6%</td>
</tr>
<tr>
<td>Ireland</td>
<td>4,581,269</td>
<td>393,800</td>
<td>9%</td>
</tr>
<tr>
<td>Italy</td>
<td>60,776,531</td>
<td>2,600,000</td>
<td>5%</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>16,783,092</td>
<td>1,700,000</td>
<td>10%</td>
</tr>
<tr>
<td>Norway</td>
<td>4,883,111</td>
<td>1,220,777</td>
<td>25%</td>
</tr>
<tr>
<td>Slovenia</td>
<td>2,054,741</td>
<td>115,000</td>
<td>6%</td>
</tr>
<tr>
<td>Spain</td>
<td>46,076,989</td>
<td>4,500,000</td>
<td>10%</td>
</tr>
<tr>
<td>Switzerland</td>
<td>7,785,800</td>
<td>750,000</td>
<td>10%</td>
</tr>
<tr>
<td>UK</td>
<td>61,827,200</td>
<td>10,000,000</td>
<td>16%</td>
</tr>
</tbody>
</table>

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

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

Italy, UK and Spain: the highest incidence of SCI

*: 8 USU + 15 SCI Units
The questionnaire: SCI entrusted to public service

SCI profile

- Public: 90%
- Private: 10%
The questionnaire: budget cuts

Reductions are particularly felt in Spain and Italy.
Which income supports? disability pension is the universal support
The questionnaire: extra-costs for families

- Caregiving
- Aids provision
- Transport
- Drugs
- Home modifications
- Housekeeping
- Rehabilit
- Temporary residence at health facility

Personal assistance
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

<table>
<thead>
<tr>
<th>Item</th>
<th>Higher quality standard</th>
<th>The same quality standard</th>
<th>Lower quality standard</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchairs</td>
<td>Netherlands, Switzerland, UK, Ireland, Spain, Norway,</td>
<td>Slovenia, Italy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special beds</td>
<td>Netherlands, Switzerland, UK, Ireland, Spain, Norway, Italy, Slovenia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mattress</td>
<td>Netherlands, Switzerland, UK, Ireland, Slovenia, Norway,</td>
<td>Spain, Italy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cushion</td>
<td>Netherlands, Switzerland, UK, Ireland, Spain, Norway, Italy</td>
<td>Slovenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shower chair</td>
<td>Netherlands, Switzerland, Ireland, Spain, Norway,</td>
<td>UK, Slovenia, Italy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catheter</td>
<td>Netherlands, UK, Ireland, Spain, Norway, Italy, Slovenia</td>
<td>Switzerland</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hygienic aids</td>
<td>Netherlands, Ireland, Norway, Slovenia</td>
<td>Switzerland, UK, Spain, Italy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoist manual</td>
<td>Netherlands, Switzerland, Ireland, Norway</td>
<td>Slovenia, Spain, Italy</td>
<td>UK</td>
<td></td>
</tr>
<tr>
<td>Hoist electric</td>
<td>Netherlands, Switzerland, Ireland, Norway</td>
<td>Slovenia, Spain, Italy</td>
<td>UK</td>
<td></td>
</tr>
<tr>
<td>Home modification</td>
<td>Netherlands, UK, Ireland, Spain, Norway, Italy</td>
<td>UK, Spain, Italy</td>
<td>Slovenia</td>
<td></td>
</tr>
<tr>
<td>Adapted vehicle</td>
<td>UK, Ireland, Spain, Norway, Italy</td>
<td>Netherlands, Spain</td>
<td>Slovenia</td>
<td></td>
</tr>
</tbody>
</table>
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
The questionnaire: barriers to employment

Italy

Switzerland
The questionnaire: barriers to employment

**UK**

- Lack of support (lack of national/regional employment strategy for people with disabilities, lack of information, lack of structures and agencies for the employment of disabled people, lack of incentives for employers)
- Lack of skills/education
- Barriers (attitudinal, legal, physical, social)
- Transportation reasons
- Lack of jobs (high unemployment rates overall)

**Slovenia**

- Lack of support (lack of national/regional employment strategy for people with disabilities, lack of information, lack of structures and agencies for the employment of disabled people, lack of incentives for employers)
- Lack of skills/education
- Barriers (attitudinal, legal, physical, social)
- Transportation reasons
- Lack of jobs (high unemployment rates overall)
Which are the supports for the employment? The importance of vocational rehabilitation

Part of rehabilitation pathway

- Vocational rehabilitation: 86%
- Training courses: 71%
- Sickness benefit/allowance: 57%
- Unemployment benefit: 57%
- Flex job: 0%
- Social assistance: 43%
- Study grants: 29%
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
Difference in terms of social inclusion between people with disabilities and without disabilities (on a scale from 1 to 10):

- The Netherlands: 6
- Switzerland: 5
- Slovenia: 5
- Spain: 7
- Norway: 3
- Italy: 5

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:

50%  
13%  
38%

Excellent  
Unsatisfactory  
Good

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ESCIF  
FAIP
### 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:

<table>
<thead>
<tr>
<th>Country</th>
<th>Association’s budget/ Total SCI persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Netherlands</td>
<td>40 €</td>
</tr>
<tr>
<td>Switzerland</td>
<td>1850 €</td>
</tr>
<tr>
<td>UK</td>
<td>62 €</td>
</tr>
<tr>
<td>Slovenia</td>
<td>1907 €</td>
</tr>
<tr>
<td>Spain</td>
<td>46 €</td>
</tr>
<tr>
<td>Norway</td>
<td>146 €</td>
</tr>
</tbody>
</table>

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

- **ACUTE PHASE**
  - Surgery and medical treatments

- Rehabilitation program
  - Physical rehabilitation
  - Social rehabilitation

Follow-up and long-term rehabilitation

interdisciplinary treatments

interdisciplinary team

home

?
And after the discharge?

At home

- Undeveloped Home care systems (except for Switzerland)
- Long-term rehabilitation not always accessible

Regional differences in aids provision and supports (Italy, the Netherlands, Norway, Spain)
Are the SCI Units and beds sufficient for the requirements of the country?

Yes:
- Germany
- Netherlands
- Norway
- Slovenia

Yes but more beds are necessary:
- Ireland
- Switzerland
- United Kingdom

No:
- Italy
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:

<table>
<thead>
<tr>
<th>Paraplegia:</th>
<th>122 days (4 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetraplegia:</td>
<td>197 days (6.5 months)</td>
</tr>
</tbody>
</table>

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
- “2012 will be the year with more cuts in social services and protection for people with disabilities.”
- Reduction in beds and worker staff
- Reduction in length of stay at SCI Units
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 sensitizazion 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.