Rehabilitation and the role of carers

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Overview

- Rehabilitation in Ireland
- WHO illness model
- A model of carer involvement (UK)
- Irish statistics – CSO and EMSP
- The role – family or paid carers?
- Carer's role in rehabilitation
- Key points

Definitions of rehabilitation

- *Service*
  - The use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society
- *Conceptual*
  - a process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function

Effectiveness

- UK and US studies support cost-effectiveness of intensive rehabilitation
- 1 RCT (n=160) and several small (n=39-76) case series
- Outcomes:
  - Reduced length and cost of in-patient stay
  - Reduced cost of community care
  - Improved earning capacity
  - Cost of UK programme recouped in 11 months
  - Cost of US programme recouped in 3 years

WORLD HEALTH ORGANISATION ILLNESS MODEL – MULTIPLE SCLEROSIS

	BODY FUNCTIONS AND STRUCTURES (organ)	**IMPAIRMENT** (person)	**ACTIVITIES** (person/environment)	**PARTICIPATION** (person/society)
CHARACTERISTICS	CNS lesions	Muscle weakness Abnormal muscle tone Cerebellar ataxia Sensory ataxia, numbness Optic neuritis Pain Fatigue Bulbar dysfunction Bowel/bladder/sexual dysfunction Cognitive dysfunction	Reduced mobility and dexterity Swallowing and speech production difficulties Incontinence Short term memory and attention difficulties	Work, relationship, housing and transport difficulties
INTERVENTIONS	Immuno-suppresson	Physiotherapy Functional / cognitive therapy Oral drugs for spasm, ataxia, pain, fatigue, intermittent symptoms and hyperreflexic bladder Botulinum toxin Intrathecal and intravesical drugs Surgery to release contractures and reduce ataxia	Therapy assessments and treatments Walking, mobility and communication aids Catheters, gastrostomy tube, Environmental adaptations, Environmental controls Cognitive retraining Support and counselling,	Social policy Mobility centres Social services: care and benefits Housing authority Vocational assessment and placement (DEA and voluntary) Residential/nursing homes
MEASUREMENT	CNS imaging CSF analysis for oligoclonal banding	Clinical exam Ashworth spasticity scale (0-4) Neuropsychological testing	Barthel index Functional independence measure (FIM) Assessment of motor and processing skills (AMPS) Kurzke EDSS	SF-36 (‘short form’) Nottingham health profile (NHP) WHO QOL MS impact scale

Health service delivery

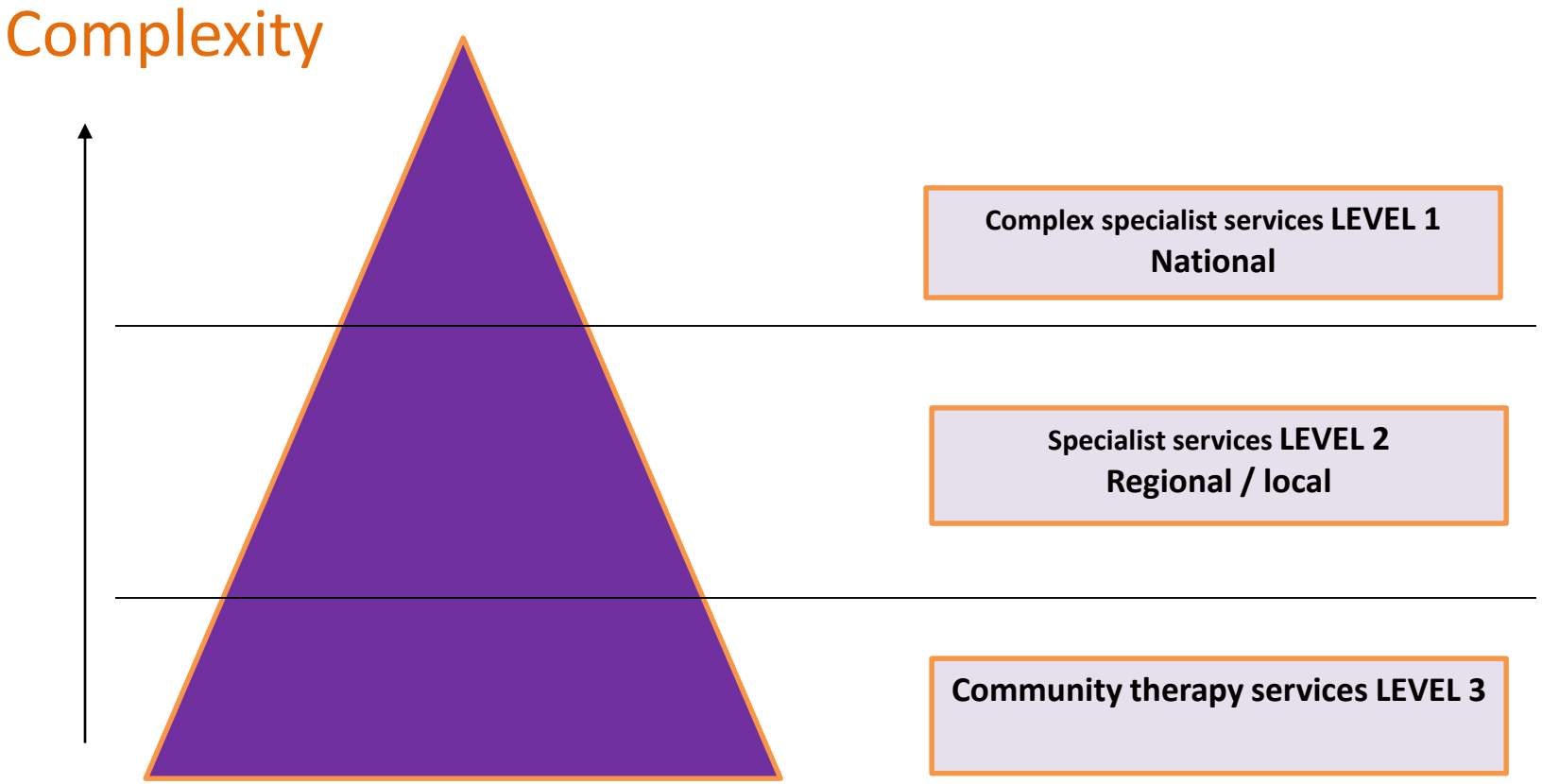
Generally

- Expectation, and demand for treatment and technological developments are outstripping available financial resource
- Until the mid 2000's Irish health delivery systems had never reformed, only grown

Specifically (for disability)

- Greater numbers of people are surviving serious injury and progressive illness with disability
- Disability and care needs are more complex

The Rehabilitation Service Pyramid



Rehabilitation Medicine Programme

- RM clinical programme developed October 10
- National policy and strategy for the provision of neurorehabilitation services (NPSPNRS) in Ireland was published in December 2011
- Model of care: second substantial draft underway
- National clinical guidelines adopted in each subgroup - ABI, SCI and prosthetics
- The National policy implementation group has met twice and agreed an implementation plan

The many roles of a carer

Paid carers / PAs

Assistance with and/or supervision of:

- Personal care
- Domestic tasks
- Passive and active exercises
- Cognitive exercises
- Household management
- Community participation: leisure, driving, work

Family members

- Physical helper
  - Personal and domestic care
- Motivator
- Health and social advocate
- Protector
- Logistician
- Income and resource gatherer
- Counsellor and soul mate

Marie Therese House Rehabilitation Unit, Hayle, Cornwall

- First conceived in 1983 as an initiative for the year of the disabled and opened in 1984
- A corresponding unit was planned in the north-east of Cornwall
- The physical environment comprises 12 in-patient beds, outpatient and day-care units
- The rehabilitation process for in-patients is managed by a multidisciplinary team.

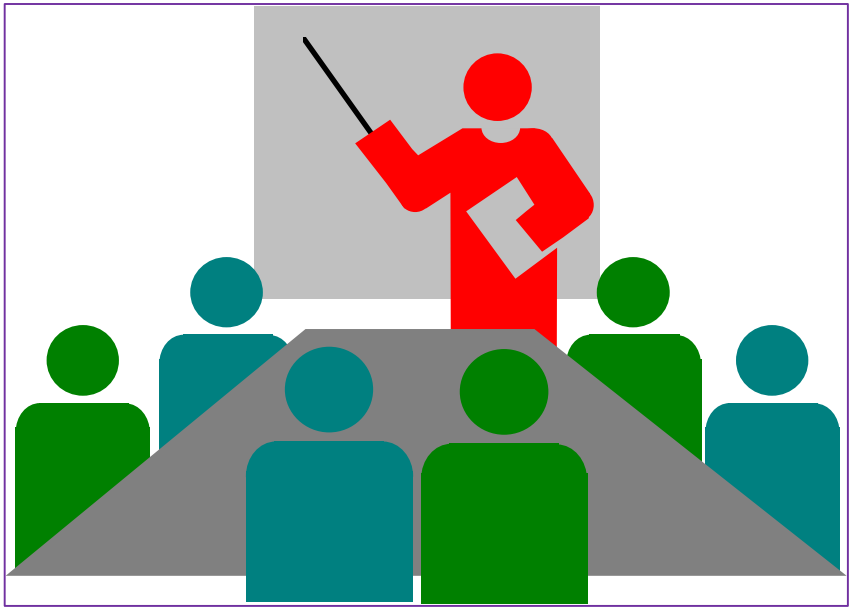
Patients' diagnoses

• Multiple sclerosis	45%
• Others	24.1%
• Stroke	13.2%
• Spinal Injury	4.7%
• Motor Neuron Disease	3.7%
• Huntington's Disease	3.1%
• Cerebral Palsy	3.1%
• Head Injury	2.1%

Other activities in the unit

- MS Education Group
- Guide Project (vocational rehabilitation)
- Consultant Outpatient Clinic
- Acupuncture Sessions
- Wheelchair Clinic
- Seminars for Health Professionals
- Disability Information Advice Line
- ENB 913 (specialist disability nursing module)

MS education programme



Aims of the programme

Set up in 1993 in response to patient need to:

- Promote a greater understanding of Multiple Sclerosis and its management.
- Improve self esteem
- Maintenance of physical fitness
- Promote good health generally
- Offer support and information to patients and family

MS education programme

One day each week for four weeks

- Each weekly session lasts for four hours
- Four elements (see next slide) to each weekly session
- Informal venue - to encourage relaxed atmosphere and interaction.
- Social aspect to the meetings - coffee and lunch
- Program designed around fitness and health
- Additional sessions about areas of special interest
- Sessions that looked at symptom control
- Open forums to promote interaction within the group involving members of MDT

MS education programme overview

- Healthy eating and diet
- Guide project
- Pharmacy and alternative medications
- Physio and exercise
- Fatigue management
- Continence
- Sexuality
- Stress Management
- Massage, reflexology
- Breathing techniques
- Other alternative remedies
- DIAN (driving eval)
- Functional matters

Participants in the MSEP

Referrals from neurologists, MS nurse and rehabilitation consultant

- Newly diagnosed people with MS
- People with established MS who are keen to be involved
- Family and /or carers of people with MS
- Other healthcare professionals

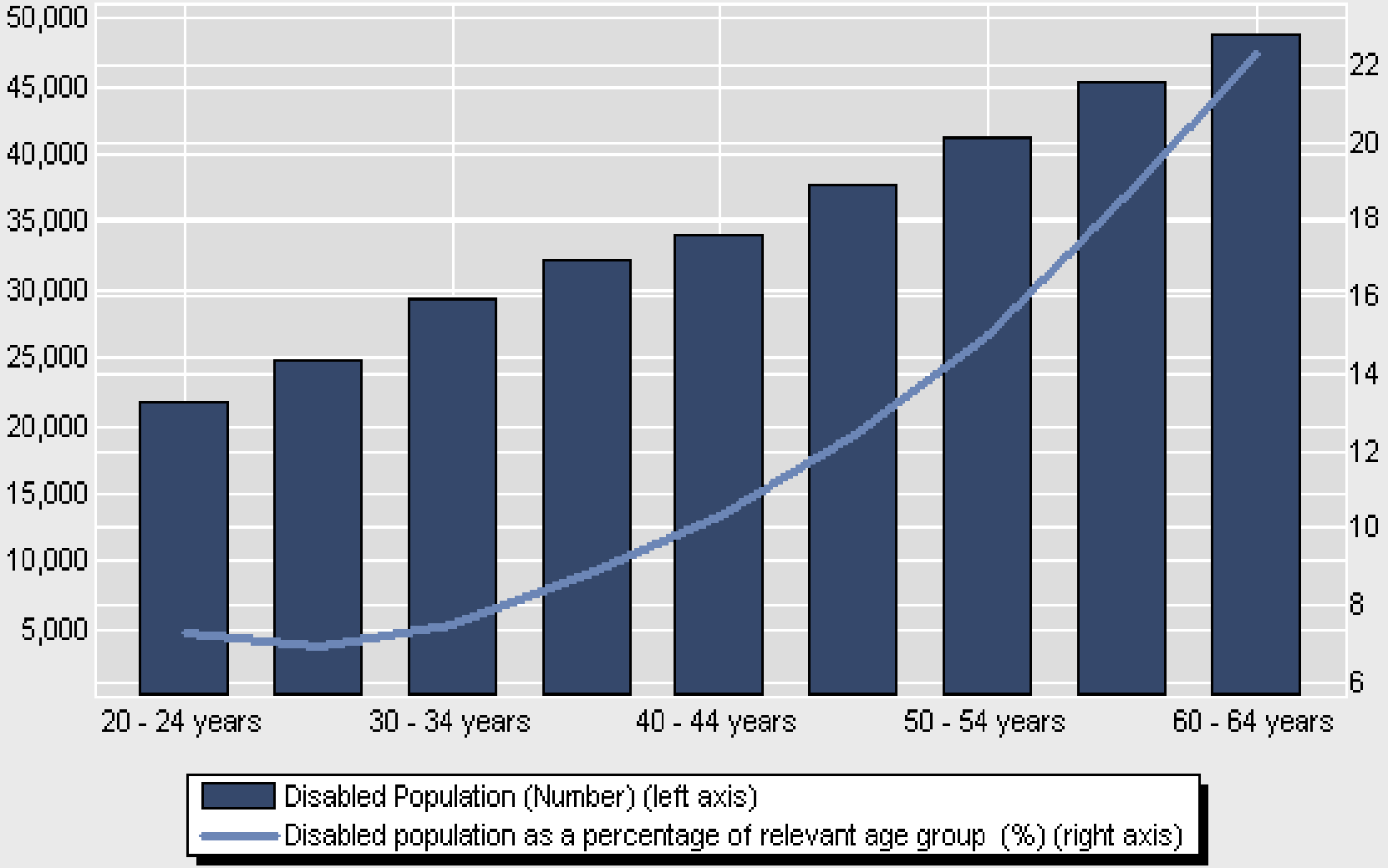
Programmed rehab admission to MTH

- Initial rehabilitation assessment
- Review of condition and investigations
- Monitoring of symptomatic treatment
- Physical and occupational therapies
- Intrathecal trial of baclofen for ITB pump
- Respite care for those with advanced MS
- Transfer from acute wards following relapse or infection
- Intravenous steroids

Outcome measures

- MRC scale (muscle power)
- Ashworth scale (spasticity)
- Visual analogue scale (pain)
- Assessment of exercise tolerance

Persons with a Disability as a Percentage of All Population
by statistical indicator and Age Group
2011, Both sexes (-)



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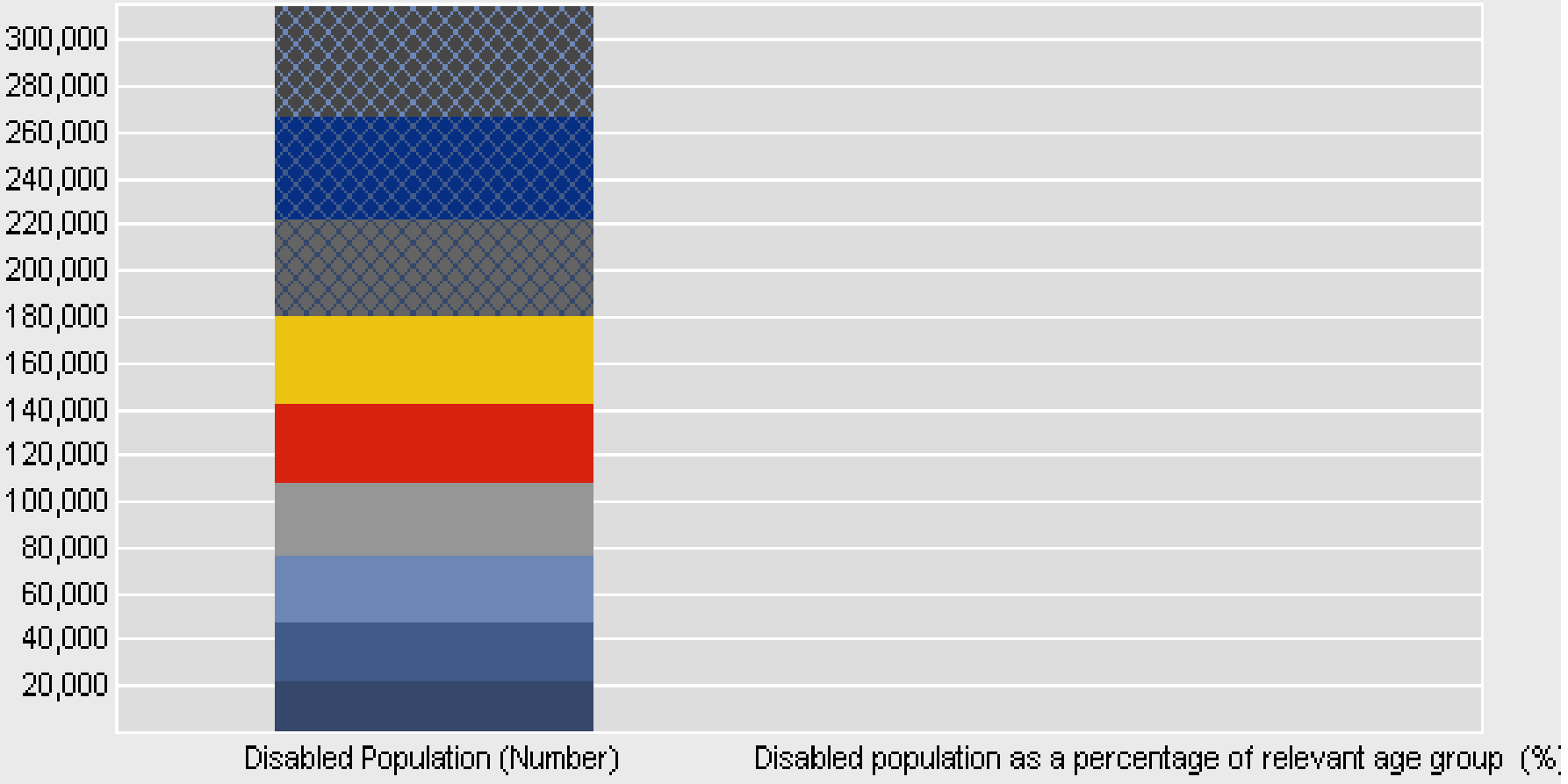
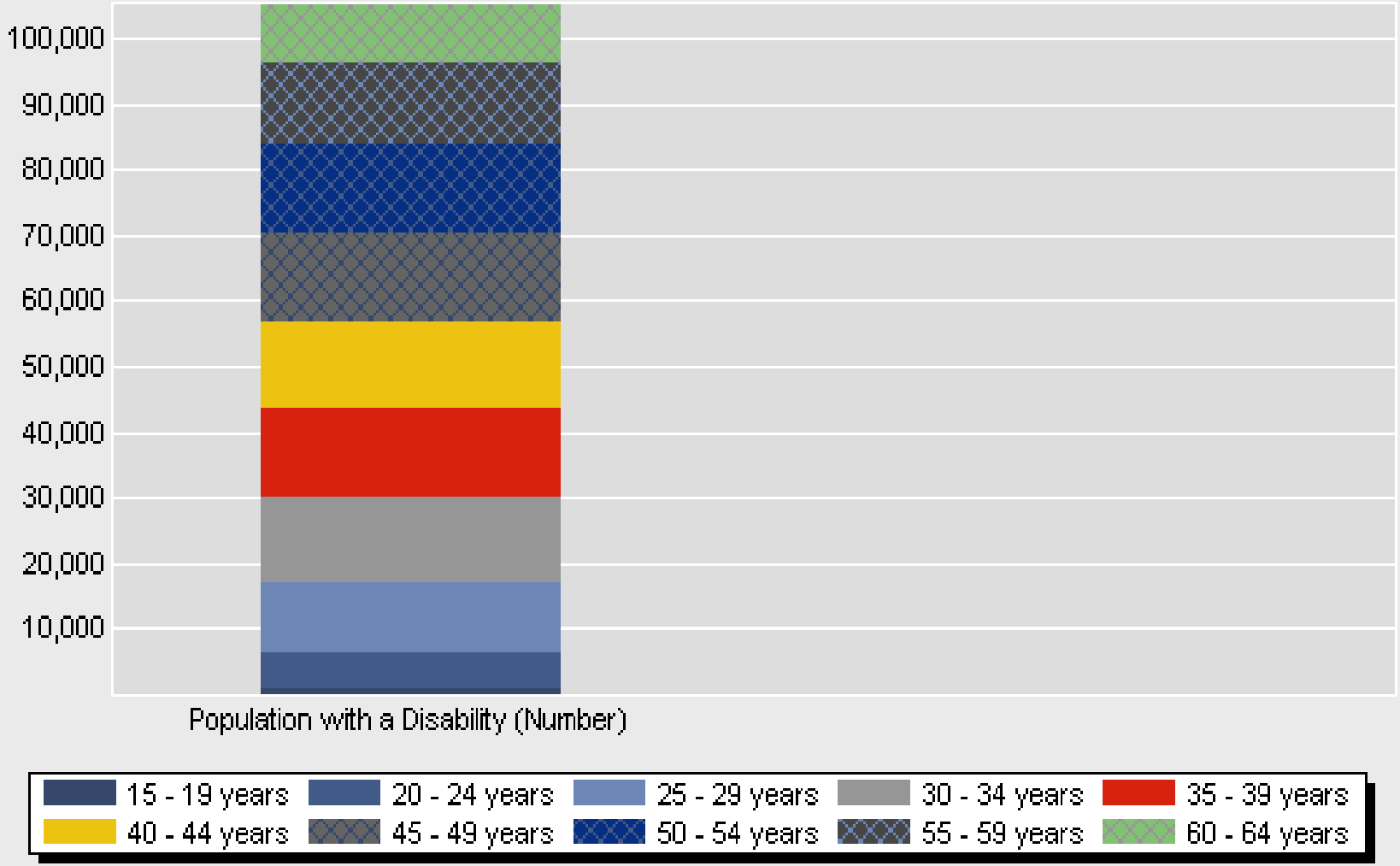


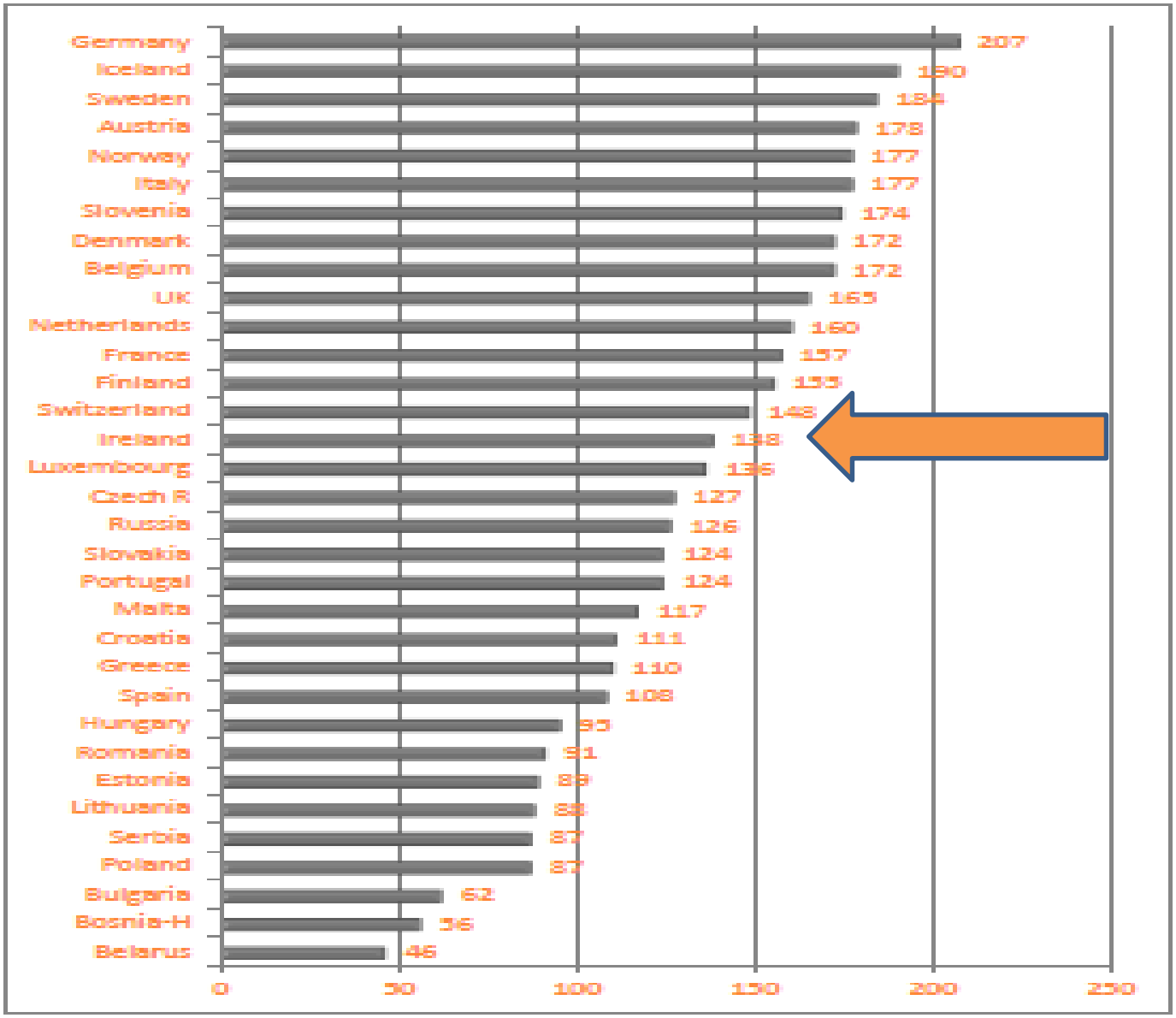
Persons with a Disability Aged 15 Years and Over
by Age Group and statistical indicator
2011, Both sexes, Population aged 15 years and over at work (-)



EMSP MS barometer 2011

Category	**Scoring on**	**Max Score**
Access to treatment	19 questions	70
Research agenda on MS	3 questions	15
Employment	8 questions	35
Empowerment of PwMS	7 questions	35
Reimbursement of costs	6 questions	30
Data collection	5 questions	25
Meds on the market	3 questions	15
Max total score		**225**

Overall MS Barometer 2011 results



MS barometer Ireland 2011

the detail

High scores

- MS training for healthcare professionals
- Access to immunomodulating therapy
- No restrictions on access to or duration of DMD therapy
- Access to symptomatic treatment and no limit to numbers or duration but…

Low scores

- Neurology to PwMS ratio
- Access to therapies (42/70)
- DMD therapies (32%; highest 70%)
- <10% access rehabilitation
- SRC* for >2500 PwMS
- Sx treatment not given in accordance with EMSP consensus statement

* Specialist rehabilitation clinic

Caregivers' role in rehabilitation

American caregivers furnished $257billion unpaid care in 2000

1. A portrait of caregivers
2. Consequences on the life of the carer
3. Caregiver – practitioner relations

Caregivers: their role in rehabilitation. Nancy Guberman, International Encyclopaedia of Rehabilitation (2010)

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Key points

- Rehabilitation services for MS patients in Ireland are patchy but collaboration planned between Neurology and RM programmes
- Carers are integrally involved in their loved one's rehabilitation but this is not acknowledged in the literature
- An initial survey of carers' participation in the rehabilitation of their 'charges' would be a productive outcome from this session.