

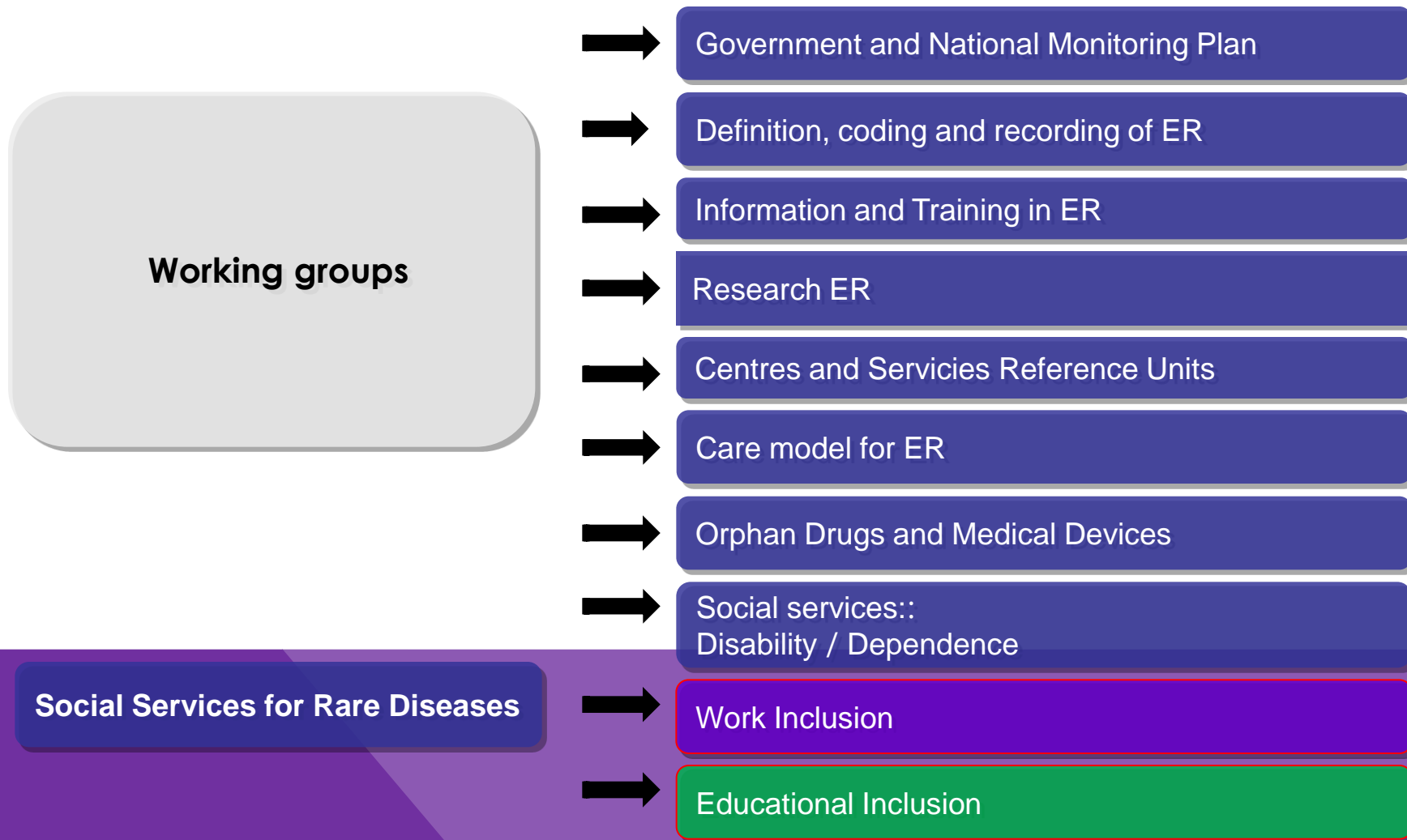


**Social policy proposals at the Spanish
national EUROPLAN conference**

**EURORDIS Membership Meeting 2015 Madrid
28-31 May, Hotel Rafael Atocha**

DIRECTORA FEDER : Alba Ancochea

SPANISH EUROPLAN GROUPS



DISABILITIES

January, 2000: Disability Scale

Real Decreto 1971/1999, de 23 of December on the procedure for recognition , declaration and qualification of the degree of disability



DIFFICULTIES

- The scale has remained unchanged since January, 2000.
- Law on the Promotion of Personal Autonomy and Care for persons in dependency situations is published in 2006.
- Until 2012 there is no chapter for Assistance of Third Person in the Disability Scale.

ASSESSMENT ON DISABILITY ON RD

EUROPLAN FINAL REPORT

(SPAIN, EUROPLAN NATIONAL CONFERENCE, 2014):

- *A person with a RD has specific social and health needs*
- *Patient's clinical history is not digitized yet (paper reports)*
- *CIF is not implemented and coding is outdated in disabilities assessment centers*



CHANGES ON DISABILITY ON SCALE

Difference between:

- **Ability:** What someone can do.
- **Performance:** What someone does when he has the necessary support

It does not reflect the age of the person with RD: the scale is applied equally to minors and adults.

Professionals who assess disability refer the biggest difficulty in the section **20% to 33 %**. In this section we can find some cronical RD with outbreaks



FEDER

PECULIARITY:

Spain is now composed of 17 autonomous communities and two autonomous cities with varying degrees of autonomy



HELP LINE

2014: Support to obtain the degree of disability according to their disease: **64**

- Legal Advice Service: **31**

2015: Support to obtain the degree of disability according to their disease :**38**

- Legal Advice Service: **16**



DEPENDENCY

- FEDER worked during the year 2014 on the **Dependency and Rare Diseases Study** of the Community of Madrid.
- This study is the second in a series of studies that FEDER began in 2009,. The first study was, **Situation of Social and Health Needs of People with Rare Diseases in Spain**
- We estimate **390.000 people** with rare diseases in the Community of Madrid
- Since the adoption of the Law on Dependency in 2006 till September 2013 **almost 198.000 persons were still pending assessment.**

DEPENDENCY AND RARE DISEASES STUDY

RESULTS:

- 117.400 persons with dissability have RD in Madrid:

Woman (64,1%): Men (35,9%)

- Grade:



- **Dependency services:** More than 60% had to wait more than a year for dependency services, between 6 and 12 months by 26.7%, and only 13.3% who had to wait less than six months.

DEPENDENCY AND RARE DISEASES STUDY

CONCLUSIONS:

- Lack of information or poor quality information for people and families.
- Excessive bureaucracy and excessive handling of documentation.
- Lack of specificity on rare disease by professionals.
- Few resources to meet their priority needs.



SOCIAL SERVICES EUROPLAN PROPOSAL

Attention to Disability and Dependence

- Promote the creation of a Social Services Law that establishes the criteria of coordination between health services , social services , employment services and education .
- Urgently approve the scales of disability rating according to the criteria of the CIF
- Unify the valuation processes of disability and dependency status to avoid conflicting reports
- Urgently allow professional assessment of disability to access medical records and implement codes CIE-10



FEDER Madrid

- Agreement with the Department of Social Services, 2010
- Constitution of a Working Group on a guide.

NEXT STEPS:

- Gather information from the Associations
- Professionals who assess disabilities (a group of 7 persons: psychologists and doctors mainly) adapt it to make it simple and practical for the assessment, in line with the scales that are currently in use.
- Transfer to the association the result of this work in due to have their agreement and it is incorporated to the Guide and published.



AIM: All the criteria listed in each disease are to be included in the scale

FEDER Andalucía

We work within CERMI – Andalucía and with the Department of Disabilities (DG de Dicapacidad) Department of Equality, Health and Social Policy

Annual meetings with the Disability Agency of Andalusia to work incidences.



FEDER Cataluña

Sessions with the Assessment Service to inform about the problems suffered by several Catalan associations on disability assessment and to work incidences, both individual and from de associations.



FEDER Extremadura

- Working Group "Advisory Council for Rare Diseases in Extremadura".
- Extremadura Health Plan Experts 2013-2020
- Extremadura Health Plan Experts 2013-2020 of ER.
- Working Group of the Health Council of Villar del Pedroso Zone.
- Education Working Group Protocol.
- Patients Regional Council of Extremadura
- Work in coordination with CERMI Extremadura.
- Work meetings with different political groups to give them information on the situation of people with RD



FEDER Com. Valenciana, País Vasco and Murcia

All actions on disability and dependency are made through CERMI of each autonomous community.

In Murcia, we have carried out activities with the Ministry of Education to improve the care situation of children in classrooms with disabilities and / or dependency



CONSULTATIONS RECEIVED BY SAJ

Perceived problems SAJ consultations concerning Disabled

- Beneficiaries are in a situation of legal uncertainty
- Legal uncertainty and regulatory dispersion
- Violation of the right to the promotion of personal autonomy and dependency care
- The system provides less coverage for their beneficiaries

CONCLUSIONS

- The type of personal support they receive more frequent surveyed people with rare diseases is that of family members living at home , as 80.9 % of the collective experience such aid , receiving 58.3 % of the affected support of close relatives on a continuous basis .



CONCLUSIONS

People have support needs in **57%** of the activities of their daily lives.

In general:

The impact of the disease in all spheres of life, focuses on the health sector from the perspective of the victims, an issue that clearly affects their view of the resources they receive dependency, which is insufficient



CONCLUSIONS

Dependency increases exponentially with age, but there are other factors that require us new benefit systems by increasing dependencies, including all age ranges, especially minors.



WHAT ARE WE DOING? SERVICES AND PROJECTS

PERSONAS



SOCIOS



SOCIEDAD



Information and Orientation Service	Service of assistance to associative movement	Political incidence and social mobilisation
Psychological Attention Service	Formation to the associative movement	Awareness Campaigns
Juridical Assistance Service	Helps	Activities of divulgation
Program to Access to Health Products	Agreements of Partners	Communication Ways 2.0
Promotion of person's networks and entities	Service of Multi-conference	Publications and Studies
Orientation of cases without diagnosis	Associative Participation	Inclusion
Formation to professionals	Service of Diffusion for the associative movement	Investigation

EUROPLAN IMPROVEMENT SUGGESTION

1. Train persons involved in the process with a particular focus children
2. And other specialized services include alternative therapies in offering services SAAD
3. Flexibility and Agility administratives procedures
4. Increase benefits for Dependency
5. Improve the accuracy and clarity of medical reports since the beginning of the valuation



EUROPLAN IMPROVEMENT SUGESTION

List of Workshops

- Social Services for RD

Additional Workshops:

- Labour Market Inclusion
- Educational Inclusion



SOCIAL SERVICES FOR RARE DISEASES

- Social Services structure
- Spanish Social Services system

The SAAD services catalogue sets out a compendium of benefits, resources and services to promote personal autonomy and dependency care. These services are not RD specific.



RECOMMENDATION AND CONCLUSION

- Spain needs a Social Services Act laying down the criteria for coordination among health, employment and educational services
- A common platform is needed for sharing information
- Urgent approval is required of the disability percentage tables following CIF international functioning classification (IFC) criteria.
- A map of the social resources available and a directory easily accessible by people are needed.
- Urgently enable access to patients' medical records by the professionals responsible for evaluating disability and introduce ICD-10 codes.
- Cooperation agreements should be made with third sector organisations
- The use of existing resources should be encouraged for disabled or dependent people

LABOUR MARKET INCLUSION

Minimum Disability of
33 %

Supported
employment

Absence
from work

Programme for
adapting to the
job post

Mobbing

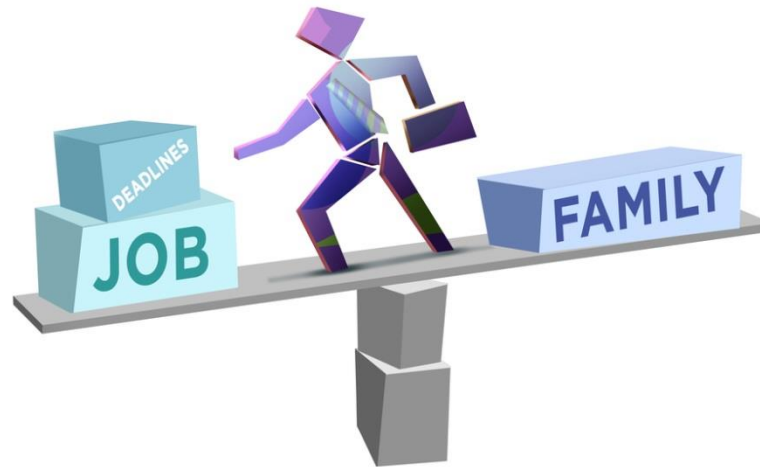
INCLUSION OF PEOPLE WITH RARE DISORDES

Some Proposed Solution

1. Inclusion and access to employment
2. Absenteeism from work
3. “Mobbing” or workplace harassment
4. Adaption and/or change of job

LABOR INCLUSION OF CARERS

Objective of improving the work-family balance of staff.
There is a need to look at the employment needs of carers.



INCLUSION OF PEOPLE WITH RARE DISORDERS

Some Proposed Solution

- Remove the closed list of diseases that lead to early retirement of ER
- Extend the paid leave while the situation remains convalescent
- The less affected by serious illness can be schooled for caregivers may be beneficiaries of the dependent child allowance.
- Care required must not be exclusively for medical or medical
- Recognition and tax credit for employers who hire caregivers affected by ER, flexible hours or telecommuting.
- Recognition of part-time work without proportional reduction in salary involved.

ATTENTION ER IN SPAIN: DATA

- Educational exclusion of children with ER : **73%** of the associations expressed dissatisfaction with inclusive education in compulsory and post-compulsory pre -stage and **68 %** in required
- Forms of schooling and curriculum unadjusted capabilities / needs of our students : **76%** of surveyed organizations consider most appropriate mode of schooling in mainstream school with support from **10%** advocated by the Center for Special Education.
- Absence of specific human and technological resources (health workers, rehabilitation , teacher of therapeutic pedagogy : **88.67 %** of associations said that the available human resources are insufficient to meet the needs of schoolchildren.
- Lack of teacher training
- Psychoeducational assessments unadjusted

EDUCATION ER IN SPAIN

NEEDS

- Educational exclusion
- modalities schooling and curriculum unadjusted
- Lack of RRHH and technology specific
- Lack of teacher training
- Psychoeducational assessments unadjusted

EDUCATION

FEDER PROPOSALS



EDUCATIONAL INCLUSION PEOPLE WITH ER: PROPOSALS EUROPLAN II

Promote Educational inclusion

- **Establish protocols for coordination** between social, health and education services to ensure the right to inclusive education .
- **Engaging education authorities**, at national and regional level , to establish guidelines for the development of protocols with students with rare diseases. The development of such a protocol should have specialist advice from associations corresponding to the given disease, and other expert groups

RECOMMENDATIONS EUROPLAN II

Recommendations and Conclusions

Encourage educational inclusion for students with RD, offering an educational response adjusted to the needs of each student.

- Inclusive culture
- Inclusive Policies
- Inclusive Practices

- A change of culture
- New educational policies
- Inclusive Practices

