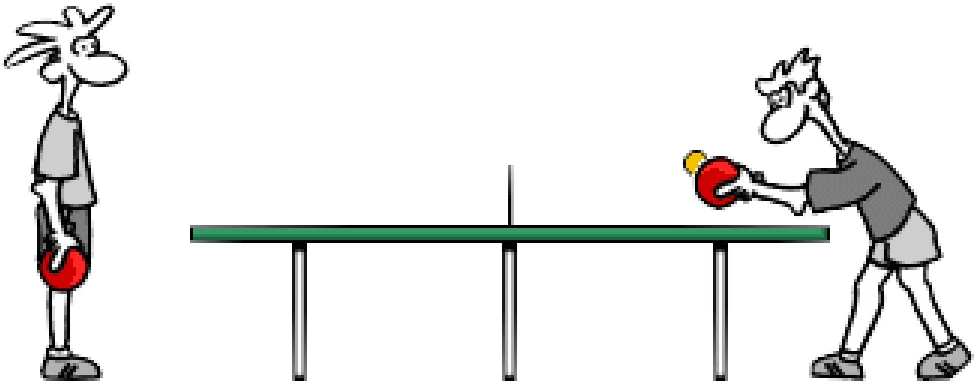
How are Member States & the EC Expert Group on RDs addressing social challenges in RDs

Raquel Castro, Social Policy Manager, EURORDIS

How we see that authorities and services handle the social integration of people living with rare diseases

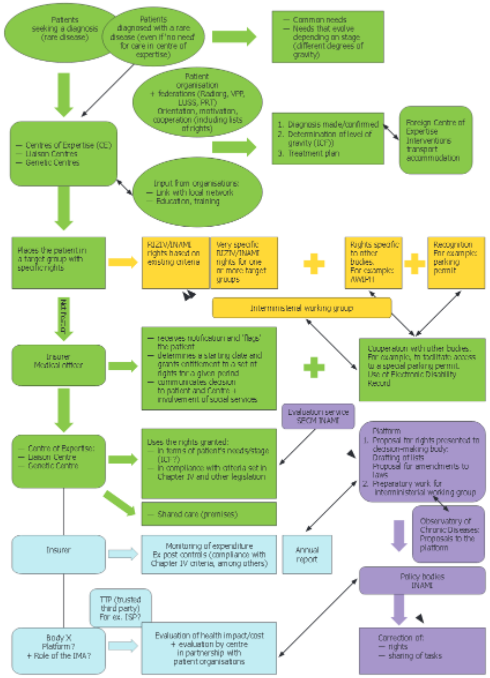


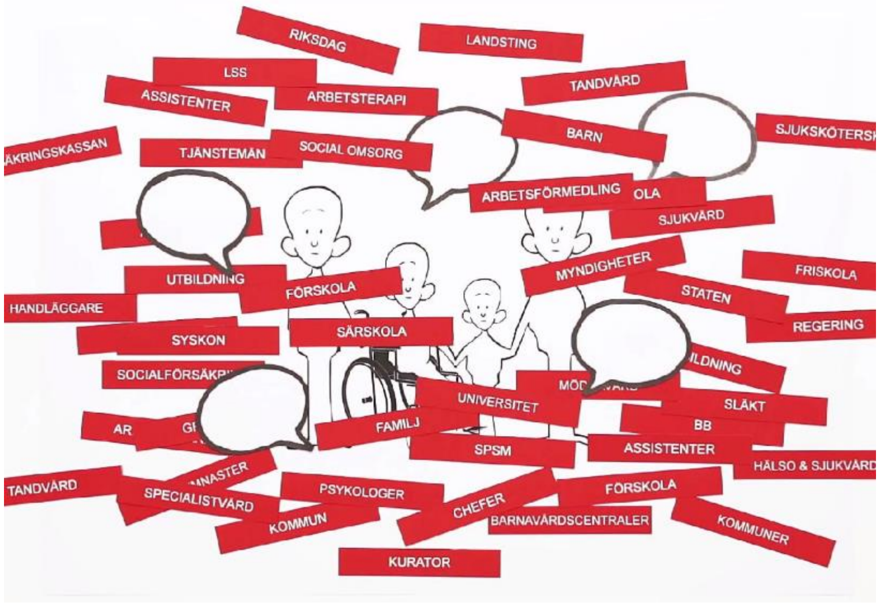
Health

Social

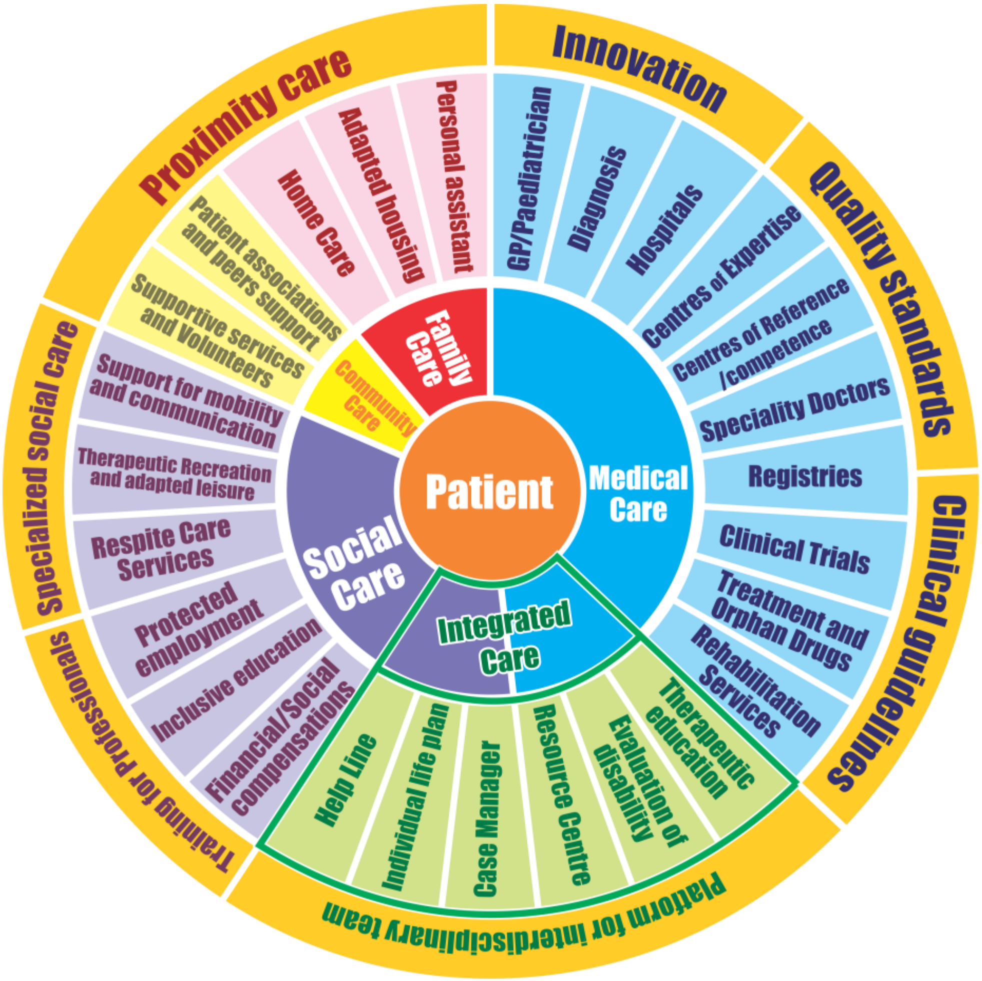
How authorities and service providers might perceive us

In most countries the care pathways are not yet structured and patients struggle to access the services and the support they need

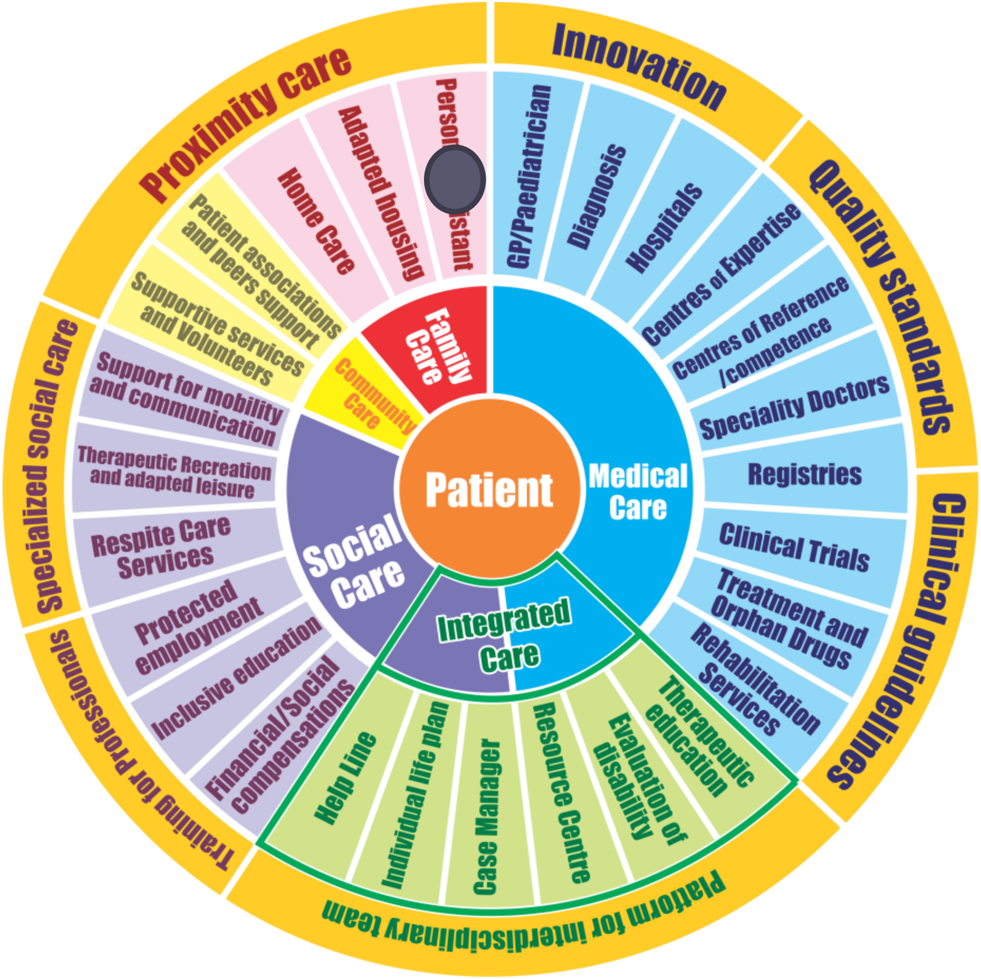




The needs of people living with rare diseases are many and require coordinated holistic multidisciplinary care



And solutions need to be implemented to avoid the “roulette” effect



Patients & other stakeholders are working on solutions to improve social integration of people living with rare diseases

Key Issues in National Plans & EUROPLAN Conferences

- Social care and national strategies/plans for rare diseases
- The patient in the centre of care
  - Care pathways & individual care plans
  - Case management to facilitate personalised care
- Transfer of knowledge and expertise
- Coordination & networking
- Supporting patients’ day-to-day challenges & integrating RDs into social services
- Social research, information and data collection and sharing
- Training professionals and patients/families
- Assessment of (Dis)abilities and (in)capacities
- Quality and good practices
- Funding
- The role of Centres of Expertise in Social Care

Key Issues in National Plans and EUROPLAN Conferences: Case management & one stop shop services to facilitate personalised care

- Care coordinator in the CEs (BE)
- Case managers, complex case managers, insertion technicians (FR, HU, ES)

- Strengthen the concept of a «case manager» in both the health and social systems (ES)
- Review the role of "case managers" and define who should coordinate the various services in different areas during all stages of life (LU Conf.);
- Coordinators for RDs at regional level to support patients/families in their juridical, administrative and socio-professional procedures (CH)
- The care plan might also identify a person who can liaise, on behalf of the patient, with the professionals involved in a person's care (UK)
- District teams and visiting nurses (NL)
- Having an operator, coordinating operations, is essential (FI Conf.)
- Patients with RDs need the support of a social worker in charge of each individual patient, e.g. at the district hospital (FI Conf.)
- Continuous counselling, follow-up and family consultation, case management (HU)
- Supporting the work of counselling & information centres for RDs, including help lines (RO)

- One stop shop services: organise a central office which would provide information on all procedures, rights, means, and support available (medical, social, professional) (LU Conf.); national competence centres (NO) and National Institute for Rare Diseases (HU)

Key Issues in National Plans and EUROPLAN Conferences: Case management to facilitate personalised care

Belgium Extracts from National Plan *(non-official English version)*

Action 7: Concentration of expertise and reinforcing of the CEs

b. introduction of a **care coordinator in the centres of expertise**

This coordinator simplifies and facilitates the patient’s pathway, including the administrative procedures that patients need to go through in order to see their rights recognised. This coordination has the following missions:

- Provide needed **information**: he represents the **link between patients and all stakeholders** (medical, paramedical and psychosocial)
- Facilitate the **links between the centre and the network** developed by the centre, as well as the **links with the local services**
- Facilitate **contacts with patient associations**
- Ensure **contacts with insurance organisms**, and all administrations involved in patients’ medical and social status
- **He is responsible for the mobilisation of patients’ rights**

Key Issues in National Plans and EUROPLAN Conferences: Care pathways and individual care plans

- Patients develop a personalised care path plan with their clinical and social care team (UK);
- Care intervention plans for patients and families which include social care (UK, RO)
- Individual care plan & care programme (SE)
- Personalised service plan made for patients and families in need of multi professional services (FI Conf.)
- Establishing patient pathways for different RDs - circuit of patient care (RO)
- Therapeutic Assistance Care Plan - tool to meet all the patients/families' social & health needs (IT Conf.)
- Electronic Health Dossier - set of data and health or socio-health digital documents (IT)
- "Master file" for the patient, accessible to the patient and used by all the different services (LU Conf.)
- Complex care protocols/models that specify the care, referral processes, health & social services (ES)
- Specialist clinical centres must have protocols in place to share expertise with local services (UK)
- Creating complex individual development protocols (HU)
- Support family caregivers with carefully tailored service (NL Conf.)
- Create a service to provide support to the patient from a very young age until his death (LU Conf.)
- Care coordinator in the CEs (BE) and case managers (FR, HU, ES)
- "Program of care" template model for all RDs, with both medical and non-medical needs considered. A check list is to be developed under coordination of the National Function for RDs with contributions from PO, medical specialists, therapists + other professionals and based on tools like the RD database from the National Board of Health and Welfare and Orphanet (SE Conf.)

Key Issues in National Plans and EUROPLAN Conferences: Care pathways and individual care plans

Ireland Extracts from National Plan
Care Pathways & delivering holistic packages of care - 4.4.1 Care pathways

RD care pathway to be developed - provide for high-quality care and assist in guiding patients through care and social services, increase efficiency of State resources and reduce waiting times for accessing support & social services

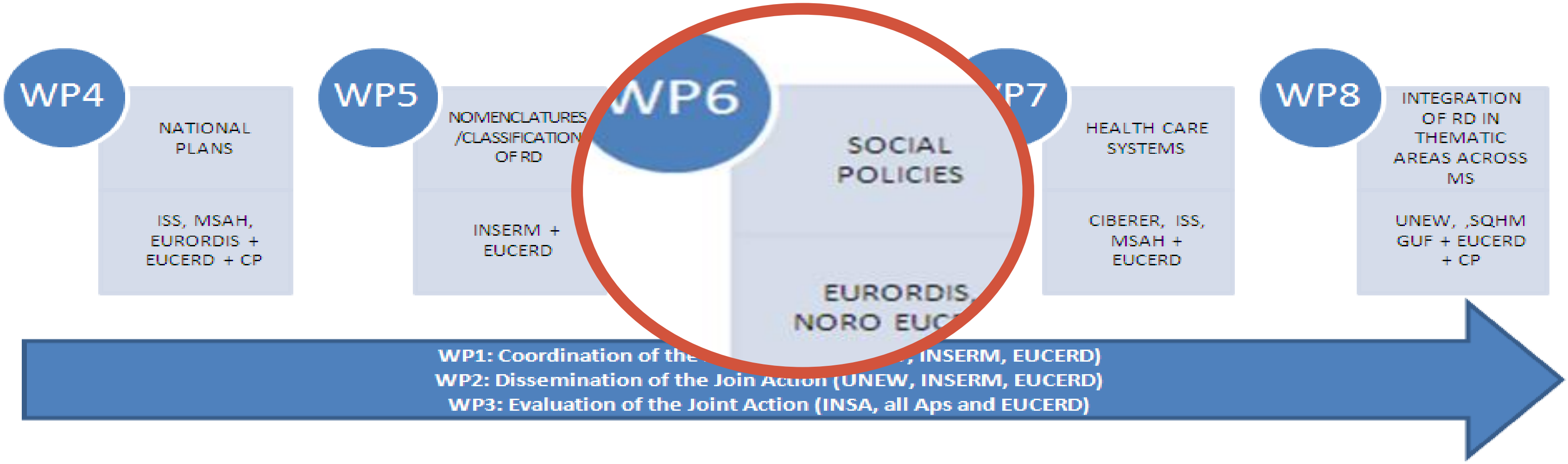
1. Identify appropriate consultants and medical care professionals and support centres
2. Provide information, educational and social entitlements appropriate to the condition
3. Where standards of international best practice exist, these should be implemented. If no international standard is available, a template needs to be created
4. The transition from paediatric care to adult care to be managed effectively and seamlessly

6.7 Delivering holistic packages of care – RD beyond the healthcare setting Holistic care:

- social isolation and exclusion
- adapting to disability
- loss of employment and independence at a young age
- the need for interdisciplinary packages of care that include psychological/counselling services
- a general lack of understanding of RDs and their implications outside of the health system in areas such as education, employment and disability

Key Issues at EU level: EUCERD Joint Action Work Package 6

Provision of Specialised Social Services and Integration of RDs into Social Policies & Services



Task 1: Identification and Mapping of Specialised Social Services

Task 2: Training of Social Services Providers

Task 3: Integration of Rare diseases into Social Policies and Services

Draft of EUCERD/CEGRD recommendations in the social field

CEGRD Recommendations on Social Care in Rare Diseases

- Social Care for people living with a RD should be addressed in national policies and in National Plans/Strategies for RDs
- The patient needs to be in the centre of care provision
- Care pathways and individual care plans should be developed and implemented in coordination between care providers
- Case management should be promoted as method to facilitate personalised care
- Expertise should be gathered centrally but needs to be made available locally in order to increase quality of care provision
- MS need to promote coordination and networking between all parties involved in care provision of patients and families affected by RDs
- People with RDs should be integrated into existing social services

CEGRD Recommendations on Social Care in Rare Diseases

- Information and data sharing should be promoted in order to facilitate holistic care provision
- Social research and surveys should be promoted in order to collect data on patients/families’ unmet social needs and on the impact of social care provision
- Professionals and patients/families need training
- MS need to continue improving incapacity assessment systems
- The elaboration and dissemination of good practices for social care in RDs needs to be encouraged
- Funding needs to be allocated to key areas which facilitate the sharing of expertise and the improvement of care good practices
- CEs have a key role in line with EUCERD recommendations on Quality Criteria for CEs (3, 4, 5, 8, 9 & 10)

CEGRD Recommendations on Social Care in Rare Diseases

Steps to elaborate the Draft CEGRD Recommendations for Social Care in RDs

1/ Workshop ‘Guiding Principles for Social Care’ 10/2014

2/ Elaboration of workshop report 03/2015

3/ Analysis of NPs & EUROPLAN Conferences’ reports 05/2015

4/ Consultation process: CERGD, SPAG, PO, Orphanet Disability, social services, professional networks 05/2015

5/ Breakout session & plenary discussion at the CEGRD 06/2015

6/ Integration of comments and delivery of draft recommendations **08/2015**

Further reading

- Communication from the Commission on Rare Diseases: Europe's Challenges (2008);
- Council Recommendation on an Action in the Field of Rare Diseases (2009);

- EUROPLAN National Conferences reports and adopted National Plans/Strategies;
- EUROPLAN Report on the 15 National Conferences (2010-2011);

- EUCERD Joint Action Documents:
  - Report - Workshop on 'Guiding Principles for Social Care in Rare Diseases'(2014);
  - Policy/literature review document 'Rare Diseases: Addressing the Need for Specialised social services and Social Policies (2012);
  - 'Guiding Principles for Specialised Social Services' (2013);
  - 'Guiding Principles on Training for Social Services Providers' (2014);

- EURORDISCare Survey – The Voice of 12000 patients (2009)

Please note that the information on this presentation is not comprehensive, it’s subjective and has the aim of stimulating debate. Contact us for complete information.

Your feedback on good practices and inspirational measures being adopted in your country is absolutely essential to support the elaboration of the EUROPLAN good practices reports

EURORDIS
Rare Diseases Europe

Madrid, May 2015

raquel.castro@eurordis.org