



## Workshop on Guiding Principles for Social Care of People Living with Rare Diseases



9-10 October, Norway

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# Why Guiding Principles for Social Care?

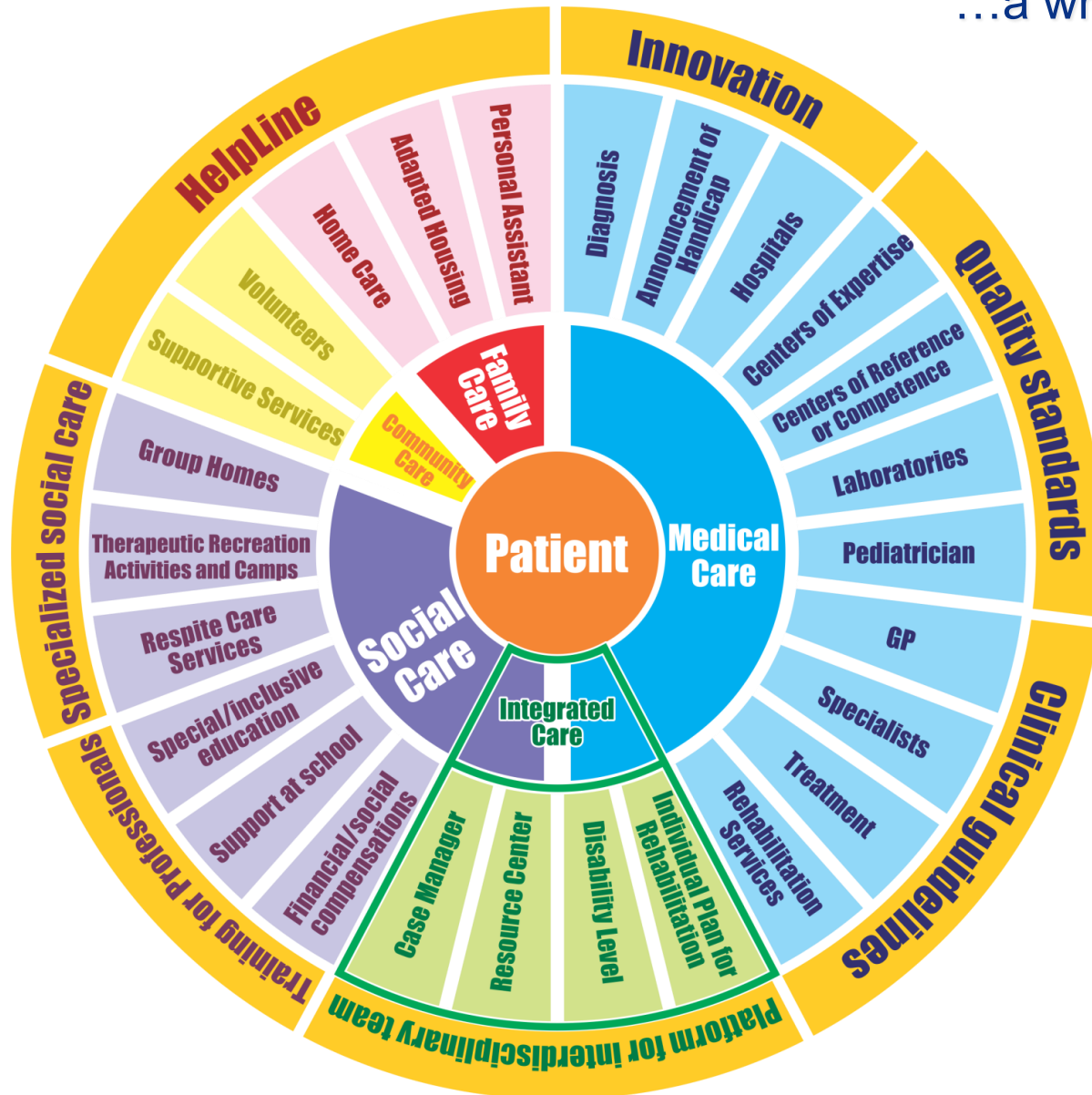
- The number of rare diseases for which no treatment is currently available is estimated to be between 4,000 and 5,000 worldwide. Source: ORPHANET
- Rarity, complexity and scarcity of treatment for RDs lead to scarcity of knowledge and expertise, lack of resources and good practices, creating huge obstacles to the performance of the necessary multidisciplinary and holistic care
- Social Services [and policies] are instrumental to the empowerment of people living with rare diseases and are essential to the improvement of their well-being and health. Source: EUROPLAN Final Report based on the 15 National Conferences
- The European Expert Committee on Rare Diseases (EUCERD) has recognised the lack of guiding principles in this field and has supported the creation of EJA's WP6 to support the Committee and MS developing social services and social policies



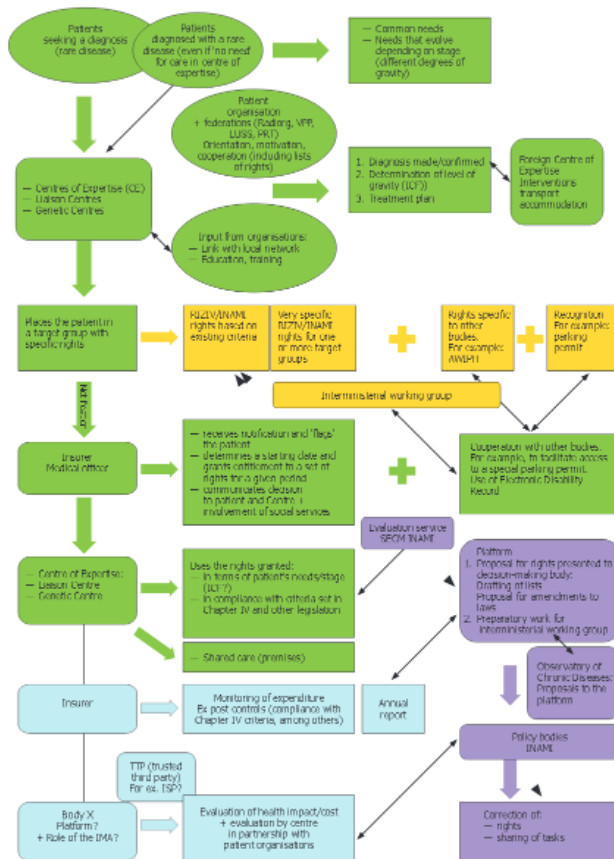
In 2014, patients' life is still  
sometimes like...

...a Russian roulette??

...a wheel of fortune??

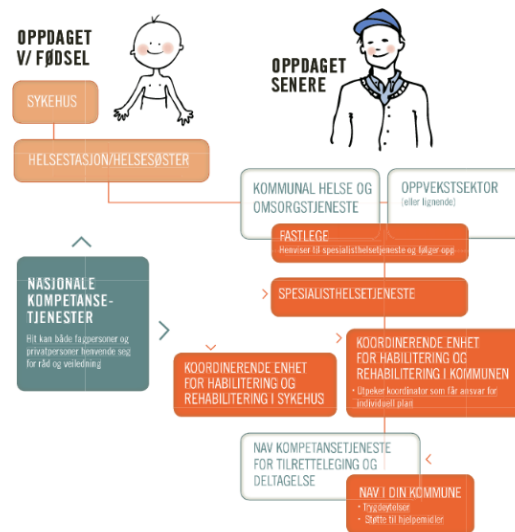


# Going through complex care pathways...



## DIAGNOSE: SJELDEN TILSTAND

Oversikten viser hvilke instanser du kan ta kontakt med:



# This workshop is done in the context of the EUCERD Joint Action Work Package 6...

Provision of Specialised Social Services and Integration of RD into Social Policies and 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

... As a first reflection exercise leading to:



Report on EUCERD guiding principles for Social Care in RD  
Draft of EUCERD recommendations in the social field





# Two previous workshops organised by the EUCERD Joint Action WP6:

‘Guiding Principles for Specialised Social Services’, Romania, 2012

‘Training for Social Services Providers’, Denmark, 2013



**Led to the development of important policy and guidance documents:**

Guiding Principles for Specialised Social Services

Guiding Principles for Training of Social Services Providers

**These documents are key:**

- To the integration of people living with RDs into social services
- For the improvement of the quality of the services provided



# Details, Agenda and Participants

**Date:** 9-10 October 2014

**Place:** Frambu Resource Centre, Norway

**Agenda** (1 ½ day):

- **Presentations on social care pathways in different countries:** France, Norway, Italy, Sweden
- **Group and plenary discussions on:** priority social issues to be mentioned in the future draft recommendation of the CERD for 'Guiding Principles for Social Care'



**20 experts from 13 countries:** Including CERD MS representatives, patients, professional experts, academia



# Preparation & Organisation of Discussions

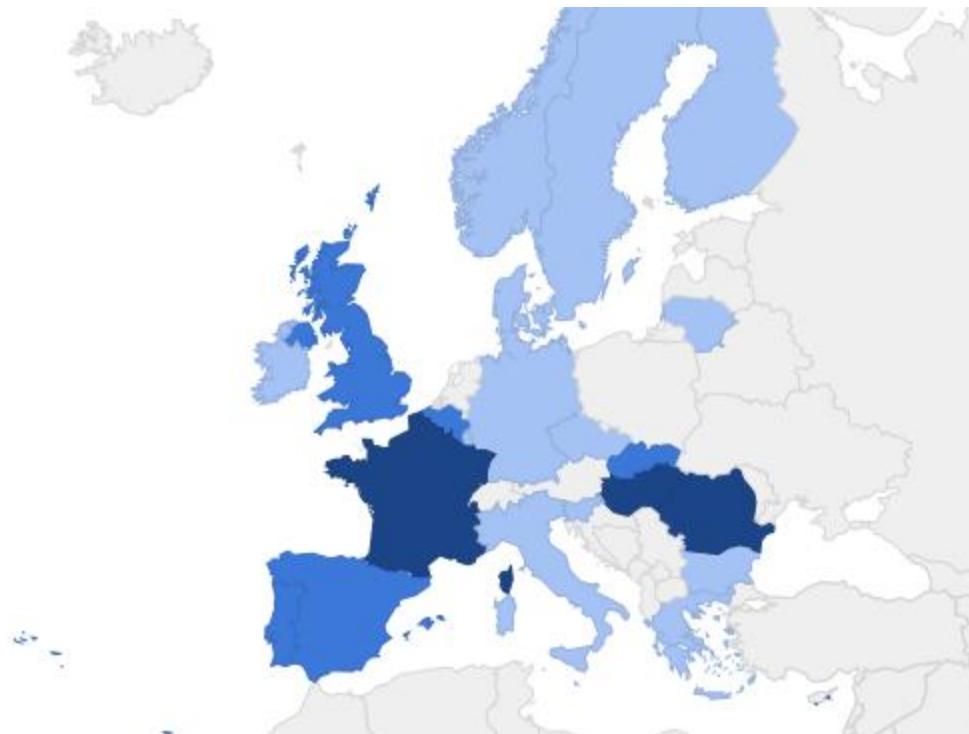
- Reading materials compiled in advance:
  - [1] Social challenges of people living with rare diseases – revision of EU policy documents, EU patient surveys and other literature at large
  - [2] Social policy/services references in National Plans for Rare Diseases, National EUROPLAN Conference reports and other important documents
- Methodology used for the discussions:
  - We've linked the challenges identified [1] to the social services and policies references in the NPs and EUROPLAN Conference reports [2]
  - Questions for the discussions:
    - Are the issues listed priority issues?
    - Are any of the current ideas/solutions from MS interesting and feasible?
    - Are there any suggestions that could be made to MS on these issues?
    - Are there any other relevant issues to be included in the draft recommendation?
    - What can be the role of CoE concerning social care?





# Preparation & Organisation of Discussions

- Important to guarantee as much input & representation as possible:
  - From participants, National Plans, EUROPLAN Conference reports
  - We are missing to analyse NP from Austria, Croatia, Cyprus, Greece, Finland, Italy, Latvia, Lithuania, Netherlands
  - And missing to analyse the EUROPLAN conference reports from Poland, Sweden, Netherlands, Serbia, Ukraine, Georgia



# Objectives of the workshop

- Introduction to EUCERD/CERD, EJA and WP6 on Specialised Social Services and Integration of RDs into Social Policies and Services
- Presentation of diverse experiences on Social Care provision for RDs in different countries
- Stimulation of debate on Social Care provision for people living with RDs
- Build consensus on a list of priority issues to be considered in the writing of the future draft 'CERD recommendations in the social field'



# Expected Outcomes

- A list of priority social services and policies issues that should be included in the draft of the EUCERD recommendations in the social field
- Suggestions on how to support MS initiating reflections on these issues and implementing measures to address them



# Food for thought – Summary of Social Issues identified

- Lack of **long term, funded and sustainable policies and structures at national levels and in the national strategies**
- Weak **coordination between health and psychosocial care, between central and regional/local infrastructures, between sectors/Ministries**
- Lack of systems to accurately **evaluate patients' disability**
- Lack of **information and understanding of disabilities and their implications in patients' lives by professionals and structures**
- **Insufficient compensation measures leading financial difficulties**
- **Geographic disparities**
- **Lack of information and support to patients**
- Insufficient sharing of **best practices**



# Food for thought – Summary of Social Issues identified

- **Lack of training of social professionals** (unprepared services and structures)
- **Scarcity** of social services and social policies/benefits; **difficult access** to those
- **Insufficient quality** of services provided
- Difficulties in **accessing and keeping employment**
- Difficulties **accessing education**
- Lack of **Case Managers** guiding patients/families (like a GPS navigation system) to access the different types of care and structures
- Lack of **personalised/flexible measures helping patients' and families to pursue their unique life project**
- Lack of **measures to remove burden from families in daily care** (personal assistants, day time structures etc.)
- Lack of systems to deal with **transition from adulthood to childhood**
- **Discrimination** in access to services





# Issues to discuss

## Structural/ framework issues:

Lack of long term, funded and sustainable policies and structures at national levels and in the national strategies

Scarcity of social services and social policies/benefits; difficult access to those

Insufficient compensation measures leading to, among other things, financial difficulties

## Ideas...

- Establish National Plans/National Strategies for RDs
- Ensure:
  - That plans have operational measures including measures on integrated care, social services and social policies
- Funding for the implementation of measures and services mentioned in the National Plans

- That there is a calendar for the implementation of actions
- That the implementation of the plan is evaluated
- Grants for research projects in Human and Social Sciences (FR) & tenders promoting social research of rare diseases (HU) to sustain needs and evaluate changes



**Do plans mention Social Policies and Social Services? Are they operational?**

**Is there funding allocated to social services and social policies?**

**What can be suggested to MS on this issue?**

# Issues to discuss

## **Integrated, Multidisciplinary, Patient Centred and Continuous Care:**

Weak coordination between health and psychosocial care, between central and regional/local infrastructures, between sectors/Ministries

Lack of Case Managers

Lack of personalised/flexible measures helping patients' and families to pursue their unique life project

Lack of systems to deal with transition from childhood to adulthood

Difficulties with local and community services and professionals providing services on daily basis

## **Ideas in the National Plans/EUROPLAN Conferences**

- Care coordinator in the CoE (BE) & bodies to coordinate health and social care services (ES)
- Case managers (FR, HU, ES)
- Organise all existing structures in one single network (GR) and establishment of networks of health care and social assistance clustered around CoE (RO)
- Develop RD care pathways (IR, RO) & care intervention plans (RO, UK)
- Complex care protocols and models that specify the care and referral processes, as well as the health services and social services (ES)
- National competence centres (NO) or National Institute for Rare Diseases (HU)
- Specialist clinical centres bring together multidisciplinary teams of health and social care professionals (UK)
- Give patients information about their condition so that they can develop a personalised care path plan with their clinical and social care team (UK)



**How to address these needs? Who can coordinate care?**

**What suggestions can be made to MS on this issue? Are the suggestions above feasible?**

# Issues to discuss

## Every day challenges:

Difficulties with local and community services

Difficulties in accessing and keeping employment

Difficulties in accessing education

Burden on the family

## Ideas in the National Plans/EUROPLAN Conferences

- Protected employment (HU)
- Therapeutic education for patients and families (HU)
- Therapeutic Recreation (HU)
- Developing Respite Care Services (RO)
- To propose special forms of support and the inclusion of children and young people with rare diseases in the school system (SI)
- Occupational reports and guides aimed at the adaptation of work stations to disabilities (ES)
- Educational guides for teaching staff (ES)
- Specialist clinical centres must have protocols in place to share their expertise with local services (UK)



**Who should initiate TRP, RCS? How can funding be ensured? How can the link with local and community services be done? – Case managers? Located where?**

**Will CoE refer patients to these services?**

**Can training for service providers help addressing these issues?**

# Issues to discuss

## Disability, Incapacities and Abilities:

Lack of systems to accurately evaluate patients' disability degree and consequent lack of compensation measures

Lack of information and understanding of disabilities and their consequences in patients' daily lives

## Ideas in the National Plans/EUROPLAN Conferences

- Implementing a new system of assessing disability and functioning (CY) & improvement of system of evaluation of incapacity supported on ICF and in RD core sets developed by Orphanet in consultation with various stakeholders (FR)
- Professionals must be properly informed about the ICF system and its application (CZ)
- Disability factsheets (FR)
- Proposal to reorganise the structure and protocols followed when evaluating RD patients and their level of disability (GR)
- Proposal to make it mandatory to all Medical Bodies as well as the Central Board of Health to contribute to the process of Disability Severity Assessment and Disability Certification Centres (GR)
- Proposal to widen the specialisation of the personnel on the committees of the Disability Certification Centres (GR)



**How can the evaluation systems be improved? Pick inspiration from ICF? Orphanet's disability core sets? Coordinate IT systems of evaluation departments in different regions? Establish evaluation protocols? What can we suggest to MS?**



# Issues to discuss

## Quality and best practices:

Insufficient sharing of best practices

Insufficient quality of services providers

## Information and training:

Lack of training of social sector professionals to deal with rare, complex cases, resulting in unprepared services and structures

Lack of information and support to patients concerning their rights and the administrative issues to handle in order to access their rights and proper compensation

## Ideas in the National Plans/EUROPLAN Conferences

- Defining the tools and interventions necessary for the improvement of social care (HU)
- Defining the development objectives of social and rehabilitation services (HU)
- Organising information campaigns (HU)
- Training social service providers & training and education programmes (RO, HU)
- Training programmes that enable health and social care professionals to better identify rare diseases to help deliver faster diagnosis and access to treatment (UK)
- Creation of a central information portal for RD (DE)



**EUCERD Joint Action has worked on guiding principles for the training of social services providers. Will MS use these? How can we encourage the sharing of best practices in social care? How can quality be guaranteed/accredited?**



# Issues to discuss

## Ideas...

### **Equity and equality:**

Geographic disparities in access to care

Discrimination in access to services

- Sharing common protocols for care provision
- Using common informatics tools and systems between different regions
- Monitoring of care provision data
- Information and awareness campaigns
- Sensitisation trainings to services providers



**Centralisation or decentralisation ?**

**Decentralisation of care, centralisation of data?**

**Decentralisation of care = duplication of services?**

**Centralisation of care = difficulties in outreaching to individual patients?**

**Centralisation in resource centres and decentralisation via outreach teams to local service providers?**

**What can we suggest to MS on this matter?**

## What role should Centres of Expertise have in the provision of Social Care?

- 3. The combined scope of all CEs within a MS covers all RD patients' needs (...)*
- 4. CEs bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services (...)*
- 5. CEs contribute to building healthcare pathways from primary care.*
- 8. CEs contribute to the elaboration of good practice guidelines and to their dissemination.*
- 9. CEs provide education and training to healthcare professionals from all disciplines, including paramedical specialists and non-healthcare professionals (such as school teachers, personal/homecare facilitators) whenever possible.*
- 10. CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals, in collaboration with patient organisations and with Orphanet.*

*Source: EUCERD Recommendations on Quality Criteria for Centres of Expertise*

## Can CoE have a role in...?

- Information provision to professionals and patients
- Training of social services providers
- Gathering social care best practices and guidelines
- Making the link between the different care providers
- Developing unit of “national competence” in social care provision

# Next steps

- Workshop report:
  - Including detailed description of the points raised during the group discussions
- Presentation of EJA WP6 progress at the next CERD meeting:
  - A first step to guarantee the engagement of MS in the draft recommendation
  - EJA WP6 will ask for a workshop back to back with the CERD's 02/2015 meeting
- Drafting the recommendation:
  - Multi-stakeholder consultations:
    - Workshop participants
    - CERD
    - Patient organisations
    - Orphanet disability projects' team
    - Professional networks, etc.
- Draft needs to be concluded by the end of EJA (08/2015)





Norway, October 2014

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