



Debrief: EUCERD Joint Action Workshop
Guiding Principles for Social Care in RDs
9-10 October, Frambu Resource Centre,
Norway



RAQUEL CASTRO

Why Guiding Principles for Social Care?

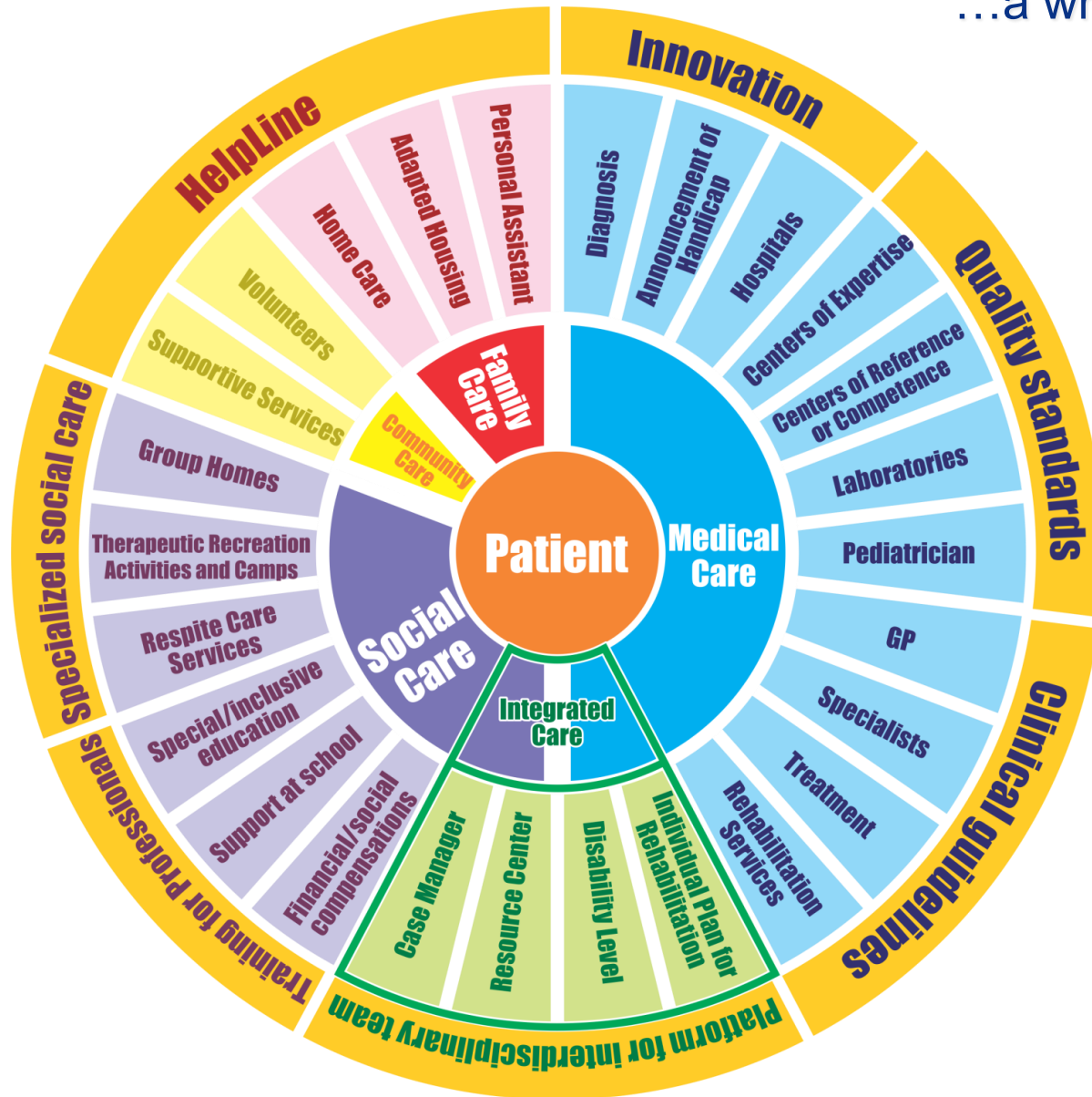
- The number of rare diseases for which no treatment is currently available is estimated to be between 4,000 and 5,000 worldwide. Source: ORPHANET
- Rarity, complexity and scarcity of treatment for RDs lead to scarcity of knowledge and expertise, lack of resources and good practices, creating huge obstacles 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



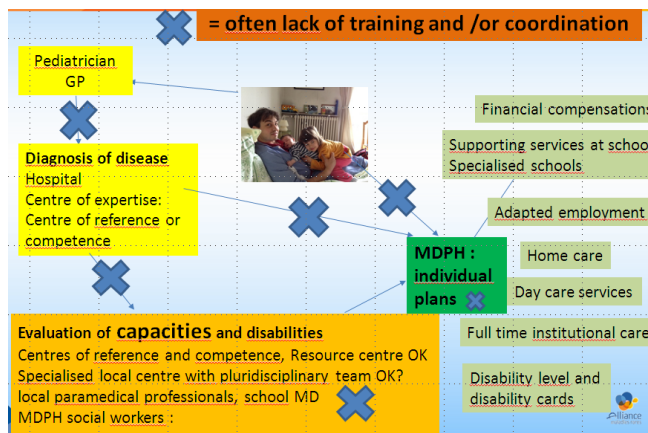
In 2014, patients' life is still sometimes like...

...a Russian roulette??

...a wheel of fortune??

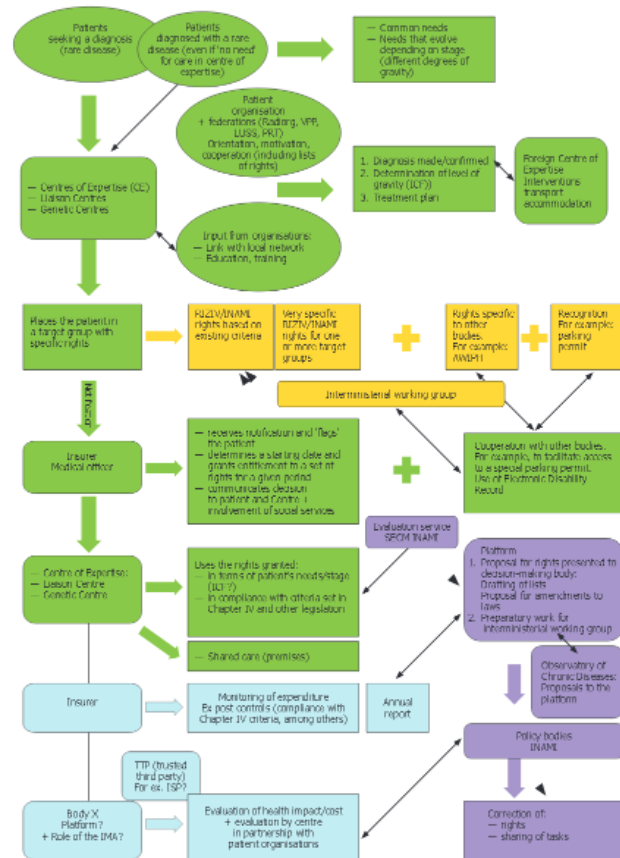
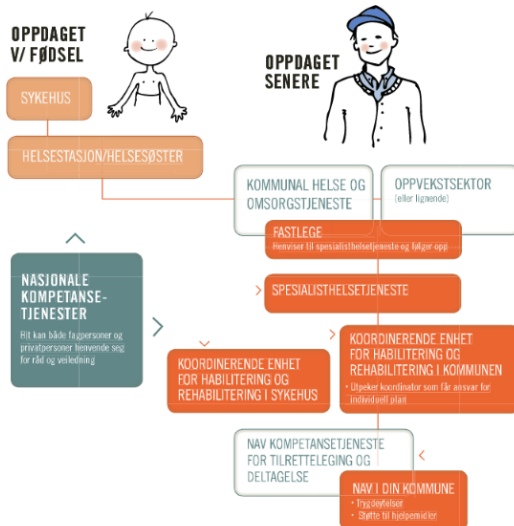


Going through complex care pathways...

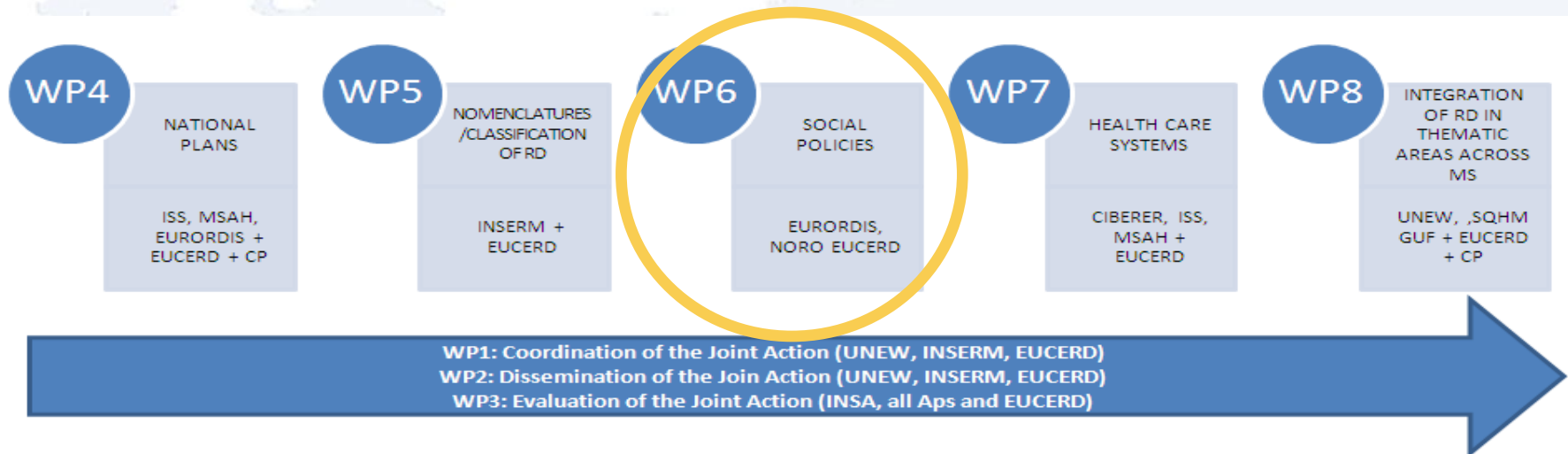


DIAGNOSE: SJELDEN TILSTAND

Oversikten viser hvilke instanser du kan ta kontakt med:



This workshop was done in the context of the European Expert Committee on Rare Diseases Joint Action Work Package 6...



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

This workshop was 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

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

Expected Outcomes

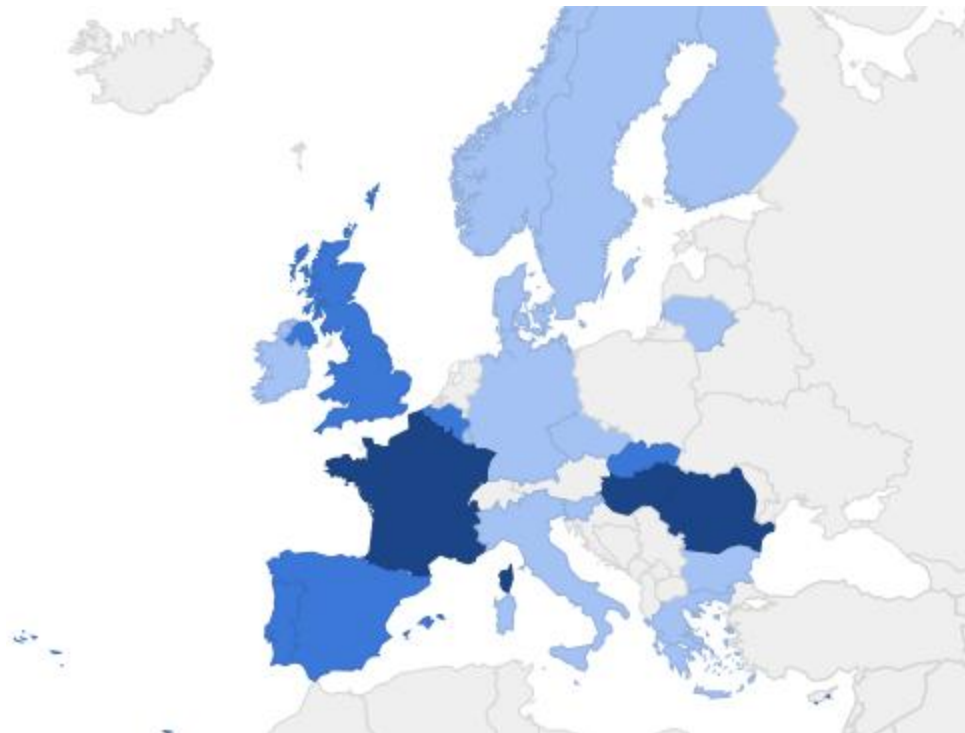
- A list of priority social services and policies issues that should be included in the draft of the EUCERD recommendations in the social field
- Suggestions on how to support MS initiating reflections on these issues and implementing measures to address them

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]
 - 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



Issues discussed

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?

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 discussed

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 discussed

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

- 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 discussed

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 discussed

Equity and equality:

Geographic disparities in access to care

Discrimination in access to services

Ideas...

- 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

1st Feedback from the Group Discussions

- All the issues listed have been considered important and a priority
 - Several reflections on the organisation of care; some main topics were constantly brought up:
 - Coordination and liaison between all care providers, regions, Ministries; networks and networking
 - Care pathways
 - Proximity care, case managers (coordinators, handlers, case management teams)
 - Individual care plans, life plans; the importance of active life, autonomy, dreams
 - Information sharing (tools, portals, trainings)
 - Training: for social professionals, for medical professionals (on social issues) and for patients and families
 - Centralisation of knowledge, decentralisation of knowledge's availability
 - The need to improve disability (and ability) evaluation systems
 - Using registries to collect some basic social data
 - Data compatibility and compatible IT systems, shared between different authorities
 - Encouraging MS to use guiding principles compiled by the EJA (Specialised Social Services; training social service providers)
- The group has considered that CoE do have roles to play, according to the EUCERD recommendation for CoE

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)**

«The patient and the family need to “drive their life car”. The road is bumpy and the way is complex. Patients might need special tools to be able to drive as well as guidance from a kind of GPS navigation system, providing them with information, directions and even alternative routes to support and empower them to successfully reach their destinations. In 2014, we are lacking most of the needed special tools and the GPS systems, and patients often depend on the good will of people they find by the road...»



EURODIS
Rare Diseases Europe

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raquel.castro@eurordis.org