Advocacy tool kit to integrate rare diseases into social services and policies

Raquel Castro, Social Policy Senior Manager, EURORDIS
Voicing the needs of people living with a rare disease and their families

Advocating for the integration of rare diseases into social services and policies

Specialised Services

Mainstream Services

Issues

Tools

Resources

INNOVCare project

RD-Action & EUROPLAN National Workshops

INNOVCare project

INNOVCare project

INNOVCare project

INNOVCare project
Voicing the needs of people living with a rare disease and their families

Complexity is not easy to grasp

What we know:

- Rare, highly complex, chronic, severely disabling
- Scarcity of information on diseases/consequences
- Scarcity and scattering of experts and resources
- Lack of treatment & lack of good practices
- Difficulties to transfer information/knowledge between care providers

The serious unmet social needs of people with a RD and their families affect their dignity, autonomy and other fundamental human rights expressed in the Universal Declaration of Human Rights and in the UN Convention of the Rights of Persons with Disabilities

1/3 of patients reduce/stop professional activity due to their disease

1/3 of families have 1 member that reduces/stop professional activity

1/3 of patients/families require assistance from a social worker

1/3 of patients/families have difficulties to meet a social worker
Voicing the needs of people living with a rare disease and their families

What we keep being asked about:

• How complex and serious is the situation of people living with a rare disease

• How many people living with a rare disease are actually suffering from severe impairments

• What are the consequences of rare diseases for patients’ and their families:
  • How is the daily life of a patient/family;
  • What are the consequence of the disease on employment, school, leisure, social life;
  • How much do families feel limited in their autonomy, life choices, financial life, etc.
  • What is the burden of coordination of care for patients and their families

Voicing the needs of people living with a rare disease and their families

Background Document: Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies (Nov. 2012)

Including patient/family testimonials:

«When you have a rare disease it feels like you are so alone and no one cares»
Janet, mid 50’s, living with Alkaptonuria, USA

«My wife, Svitlana, Yuliya’s mother is a wonderful woman! Her work deserves other publication – “how mothers fight with a Rare Disease at home”. There is no professional help at home – for our category, a staff is not stipulated, there are no volunteers»
Vitaly Matyushenko, father of Yuliya, 5 years old, living with Spinal Muscular Atrophy, Ukraine

«I hope that there will be a good and nice place for her when she leaves home, that there will be nice people around her who will take good care of her, especially when we – her parents – are not here anymore. That some nice people will bring her birthday presents, bring her home for Christmas, and take her to see places that will bring her joy»
Jane Villemoes, mother of Cecilie, 14 years old, living with Angelman Syndrome, Denmark
Voicing the needs of people living with a rare disease and their families

Rare Barometer & INNOVCare project survey on daily needs of people living with a rare disease and their families

Questionnaire out in June 2016 -> recruiting your patient/family community is key

Results can inform your advocacy work -> preliminary results out in September 2016

More information in the next presentation by Sandra Courbier...
Voicing the needs of people living with a rare disease and their families

EURORDIS Position Paper on Social Challenges of People Living with a Rare Disease (2017)

• **Working group**: EURORDIS staff & Social Policy Advisory Group
• **Consultations**:  
  • EURORDIS Public Affairs Committee,  
  • EURORDIS Policy Advisory Group  
  • Members at large (consultation via members news and discussions at EMM 2017)
Voicing the needs of people living with a rare disease and their families

Gather your advisors:

People living with a rare disease
• To share their first-hand experience living with a rare disease;
• To participate in internal discussions on your advocacy strategy and key actions in regards to social policy;
• To represent your patient community at important meetings, conferences and discussions with stakeholders.

Professionals in the social field
• Social workers;
• Psychologists;
• Teachers;
• Sociologists;
• Etc.

EURORDIS Social Policy Advisory Group:
13 patient representatives, 11 countries
Diversity of diseases
Diversity of professional profiles in the social field
Specialised Social Services 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
Integration of rare diseases into social services and policies

Background Document:
Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies’ (Nov. 2012)

Good Practices::
‘Guiding Principles for Specialised Social Services’ (2013)

Map of Specialised Social Services in Europe
## Integration of rare diseases into social services and policies

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Integration of rare diseases into social services and policies

What we know:

Due to the combination of rarity, complexity and lack of treatment:

• Patients and families need multidisciplinary, continuous and life long care and support;
• They often need to be followed simultaneously by a set of national, regional and local health, social and support services which are usually managed by different service providers and authorities.

People with a rare disease experience barriers when accessing mainstream health and welfare services:

— Care systems are usually designed around common diseases;
— Mainstream services are not flexible enough consider unprecedented health needs;
— Care systems are extremely difficult to navigate for patients and families;
— Care pathways are fragmented;
— Lack of communication/coordination between the health, social and local support services;
• There is lack of information on diseases and their consequences;
• Professionals are insufficiently informed and trained to care for people living with a rare disease and tend to be reluctant to treat patients due to the complexity of their disease;

In most cases, the management and coordination of care has to be done by patients and families, which places a heavy burden on family life.
Integration of rare diseases into social services and policies

People Living with a Rare Disease and their Family

Health

Social

Local
Integration of rare diseases into social services and policies

Commission Expert Group on Rare Diseases
Recommendations to Support the Incorporation of Rare Diseases into Social Services and Social Policies

Advising EU Member States and the European Commission on issues that should be considered when organising holistic care for people living with a rare disease within national health and social care systems

More information in the next presentation by Dorica Dan...
Integration of rare diseases into social services and policies

Training for social services providers:

• ‘Guiding Principles on Training for Social Services Providers’ (2014)
• Examples of training programmes for social providers (2014)
Integration of rare diseases into social services and policies

Reach out to the social workers association in your country:

- Various National Alliances are involving social workers in their activities and conferences;
- EURORDIS can ask the International Federation of Social Work Europe to support you in finding a contact person in your country.

EURORDIS has signed a MoU with the International Federation of Social Workers Europe:

- Raise awareness of rare diseases amongst social service providers;
- Joint-presentations at international social work conferences.

Pass by the ECRD poster area during tomorrow’s coffee break to meet Ian and Fran from IFSW-Europe: IFSW-Europe, EURORDIS, Frambu and NoRo resource centres submitted a joint poster on “Empowering Partnerships: Putting people with a rare disease in the driving seat”
Integration of rare diseases into social services and policies

Innovative care pathways promoting integrated care for rare diseases

INNOVCare project (2015-2018)

More information in the next presentation by Raquel Castro...
Another inspiring case-management project presented later by Stephanie Jøker Nielsen...
RD-Action & EUROPLAN National Workshops

The workshops are patient-led, organised by National Alliances in conjunction with EURORDIS

➔Use this opportunity to:

• Voice patients’ daily life and social needs;
• Ensure that the patients’ and families’ needs are addressed;
• Attract all stakeholders relevant in the field of rare diseases;
• Promote the implementation of the Commission Expert Group Recommendations to incorporate rare diseases into social services and policies
  • Assess their transferability into the national health system to make the best use of these policies (that EU MS contributed to adopt)
  • Bring together national existing initiatives and policies;
  • Help steer the decision-making process on RD national policies

• Workshops will specifically address 1-3 thematic priorities identified by National Alliances
• Workshops can take the form of a conference/round table:
  • One specific national event
  • Organised as part of the Rare Disease Day
  • Organised within a broader conference

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Think out of the box – social innovation

How can it be an opportunity for us to promote the integration of people living with a rare disease and their families into social services and local support services?

Come back for the 2nd part of the workshop, with social innovation expert Anette Scoppetta...
Recap of important next steps

- From now, over the upcoming years:
  Promote de implementation of the Commission Expert Group Recommendations on social services and policies

- From now until October:
  Rare Barometer/INNOVCare survey on patients’ and families’ daily life and social needs

- From this autumn and throughout next year:
  EURORDIS position paper on social challenges

- From now until 2018:
  INNOVCare project & related issues: integrated care, case management, social innovation
Other issues coming up...

We’re currently doing homework to identify important issues in the social field to feed:

• The work on our Position Paper
• The reflection on our common strategy in the social field: advocacy actions, future projects, etc.

✓ Stay tuned
✓ Get involved so we can take action together
✓ Keep us in the loop about the situation at national level & your projects
Edinburgh, May 2016
raquel.castro@eurordis.org