



Achieving Holistic Person-Centred Care to Leave No One Behind

A contribution to improve the everyday lives
of people living with a rare disease and their families

May 2019

eurordis.org/carepaper

Workshop: Making the best use of the position paper

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Plan for the day

9:30-10:00 Overview of the position paper and identification of main target audiences with participants *Raquel Castro, EURORDIS*

10:00-10:30 "Do's and Don'ts" while presenting the Position Paper to policy makers *Lene Jensen, Rare Diseases Denmark*

10.30-11.00 Coffee!

11:00-12:30 Work in groups: Setting priorities within our recommendations

12.30-13.30 Lunch!

13:30-15:00 Work in groups: Developing a product and/or a strategy to present the position paper

15:00-16:30 Presenting the products to a panel of stakeholders who provide feedback and suggestions for improvement

Overview of the position paper

1 Executive summary

2 Impact of rare diseases on daily life: understanding the specific challenges

3 Taking action can significantly improve the lives of millions of people living with a rare disease in Europe

4 Our recommendations

5 A framework of strategies for a comprehensive approach to ensure holistic care for rare diseases – 3 pillars

6 Conclusion: the time to act is now

7 About this position paper

The ambition of EURORDIS is to have holistic care provided to the 30 million people living with a rare disease in Europe, and their families, by 2030



The time to act is now!

Louis and Matthieu, Becker muscular dystrophy, France

People living with a rare disease
should be integrated into a society
that leaves no one behind



Jorge and Maria, Prader-Willi syndrome, Mexico

It is urgent to address the serious unmet needs

The time to act is now:

- Sustainable Development Goals
- European Pillar of Social Rights
- United Nations Convention on the Rights of Persons with Disabilities
- The 24 European Reference Networks
- European Network of Resource Centres for Rare Diseases
- National plan for rare diseases in 25 EU MS
- All stakeholders ready to engage and to co-create policies/services

Making holistic care a reality for people living with a rare disease

Pillar 1

Quality and
adequate social
services and
policies

Pillar 2

Integrated care:
bridging health
and social care

Pillar 3

Equity of rights
and opportunities



**All stakeholders
have a key role
to play**

**Only together, will we ensure
that no one is left behind**

We call upon
the EU, all European countries
and **all stakeholders**
within the health and social sector, **to:**

- ✓ **Disseminate**
- ✓ **Take action**

The time to act is now!

Our recommendations to achieve holistic care for people living with a rare disease and their families, by 2030



42 specific recommendations.
Print-out in your conference bag!
Full paper at www.eurordis.org/carepaper

Our recommendations to achieve holistic care for people living with a rare disease and their families, by 2030:



1. Making full use of EU instruments and European networks
2. Creating a supportive political environment at national level
3. Gathering and disseminating knowledge and good practices
4. Implementing specific mechanisms that ensure integrated care
5. Meaningful engagement in design and implementation of policies/services
6. Ensure access to adequate social services and social protection
7. Ensuring the recognition and compensation of disabilities
8. Creating conditions for access to adapted and sustainable employment
9. Implementing specific mechanisms for empowerment
10. Eliminating all types of discrimination

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10. **Eliminating all types of discrimination**

Problems to solve: politics and structures

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Problems to solve: national politics

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Problems to solve: knowledge

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Problems to solve: coordination

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Problems to solve: influence & capacity-building

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Problems to solve: access & compensation

**Who are *all*
stakeholders?**

**Who do we need to
share the paper with?**

**Who do we need
to convince?**

Results of interactive exercise with workshop participants:

National authorities

Policy Makers

Local authorities

Social Care Providers

Health Care Providers

Organisation for persons w/ disabilities

Patient Organisations & Advocates

Health Industry

Researchers & Scientists

Regulators

Payers

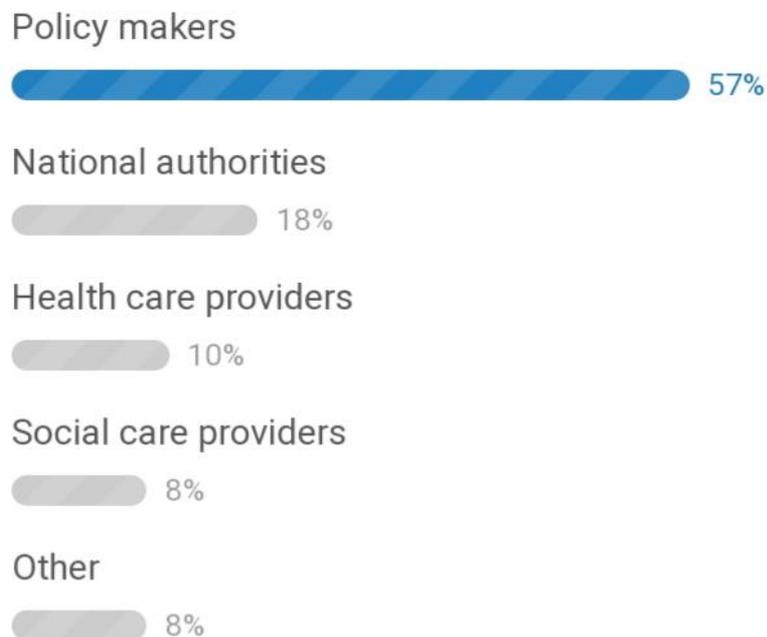
Families

Society

Educators

Results of live pool to workshop participants:

 In your country, which stakeholder will you approach first to convince them to take action for holistic care for rare diseases?



Voting closed

 In your country, who do you think will be the most difficult stakeholder to convince to take action for holistic care for rare diseases?



Voting closed

Work in Groups - 11:00-12:30 - Volunteer Moderators & topics

- **Group 1:** Clara Hervás, Public Affairs Manager, EURORDIS – **problems: politics and structures;** Focus on **reco headers 1 and 10**, with a total of 5 specific reco's
- **Group 2:** Mandy Andrews, International Foundation for Integrated Care, Scotland - **problems: national politics and lack of coordination.** Focus on **reco headers 2 and 4**, with a total of 8 specific reco's
- **Group 3:** Valentina Rupel, Institute for Economic Research, Slovenia - **problem: knowledge.** Focus on **reco header 3** with a total of 5 specific reco's
- **Group 4:** Ivana Badnjarević, NORBS, Serbia (EURORDIS SPAG) - **problems: influence and need for capacity building.** Focus on **reco headers 5 and 9** with a total of 8 specific reco's
- **Group 5:** Eleni Antoniou, National Alliance for Rare Disorders, Cyprus (EURORDIS SPAG) - **problems: acces and compensation - social services, protection and employment.** Focus on **reco headers 6 and 8**, with a total of 9 specific reco's
- **Group 6:** Maria Montefusco, Rare Diseases Sweden (EURORDIS SPAG) - **problem: Access and compensation - disability.** Focus on **reco header 7** with a total of 7 specific recommendations

Thank you!

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Afternoon: Panel of stakeholders

Moderator: Lene Jensen, Rare Diseases Denmark

Encarna Guillen-Navarro @encarna_guillen, *Hospital Clínico Universitario Virgen de la Arrixaca; former Regional Health Minister of Murcia, Spain* –roles: health care provider; policy maker

Emilia Severin, *Researcher, Department of Genetics of the Carol Davila University of Medicine and Pharmacy, Romania* - roles: academic/researcher; policy maker

Mandy Andrews @mandynetwork, *International Foundation for Integrated Care, Scotland* – roles: policy maker, improvement perspectives

Victoria Hedley @RareDiseasesEU, *University of Newcastle, UK* – roles: ERN coordinator, academic, policy maker

Thank you!

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