

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

Avril Daly, EURORDIS EURORDIS.ORG

For 85% of people living with a rare disease, the disease impacts upon several aspects of their health and everyday life





EURORDIS. 2017. Juggling care and daily life: The balancing act of the rare disease community. Survey performed via EURORDIS survey initiative Rare Barometer Voices 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



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





Holistic Care





Holistic Care 360° spectrum of health, social and everyday needs



Holistic Care

- Being aware of our needs
- Effectively providing timely, high-quality care
- Breaking down barriers in access to care, treatment, and all aspects of social inclusion
- Enabling us to fully enjoy their fundamental human rights





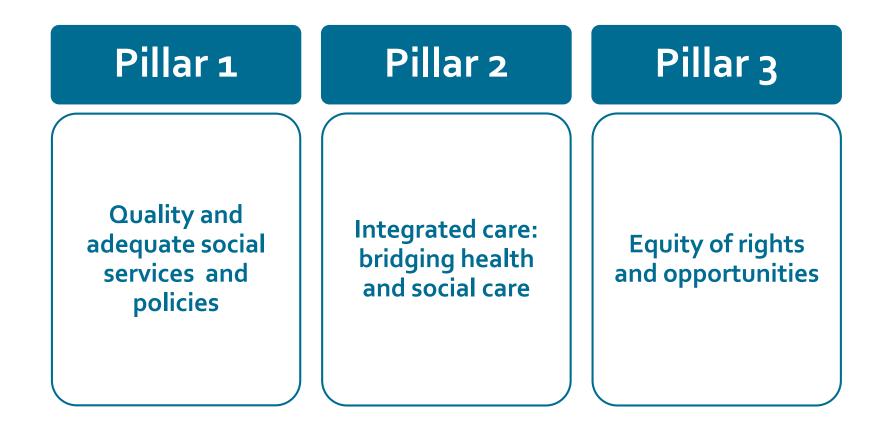
It is urgent to address the serious unmet needs

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





All stakeholders have a key role to play

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

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

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



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

✓ Disseminate✓ Take action

The time to act is now!



Thank you Santander



