

Disability: unveiling the invisible double-burden of rare diseases

Perspectives of people living with a rare disease: results of European-wide survey on the social impact of RD

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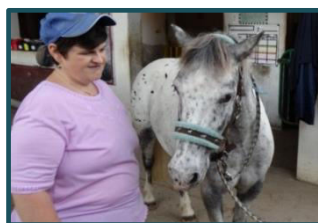
ECRD, 12th May 2018, Vienna

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“Disabilities is an umbrella term, covering **impairments, activity limitations, and participation restrictions**. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations”

World Health Organisation



Juggling care and daily life: The Balancing Act of the Rare Disease Community

*First Europe-wide survey on social impact of rare diseases,
involving 3,000 rare people living with a rare disease & carers*

Study performed via Rare Barometer Voices and within the EU-funded INNOVCare project



A EURORDIS INITIATIVE

www.eurordis.org/voices

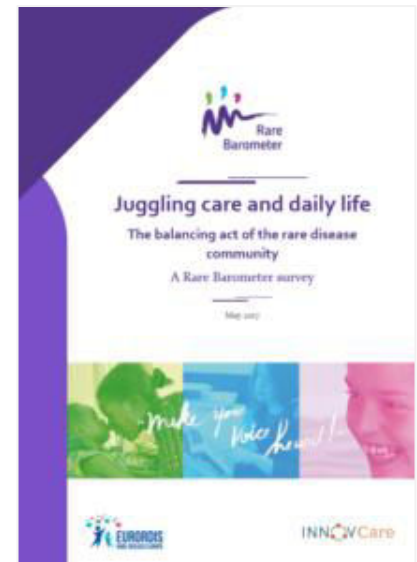


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Juggling care and daily life: The Balancing Act of the Rare Disease Community

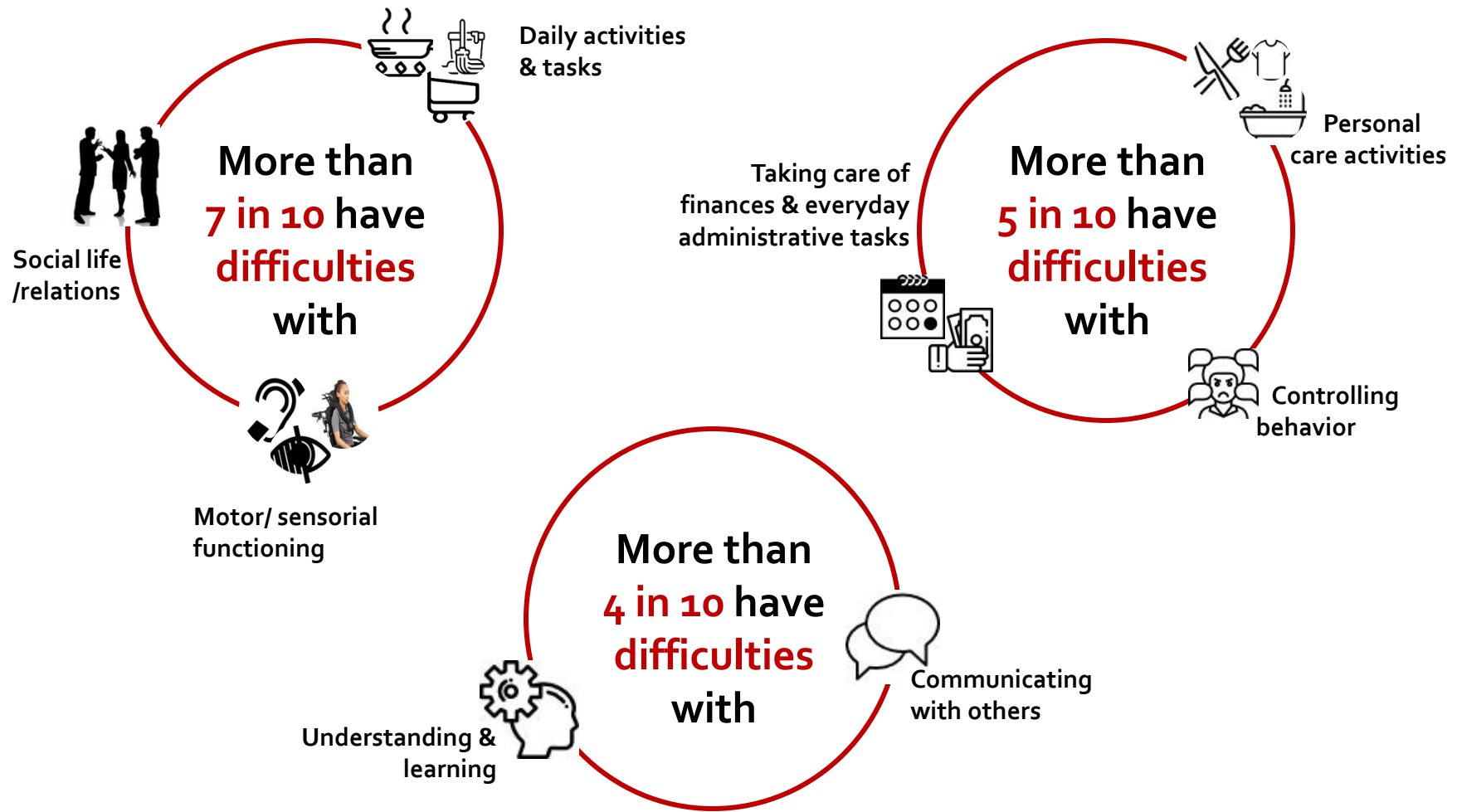
First Europe-wide survey on social impact of rare diseases

- Carried out via Rare Barometer Voices, EURORDIS survey initiative
- Over **3000** people living with a rare disease & carers participated (*62% patients; 48% carers -> some are both*)
- **802 diseases, 42 countries**
- Performed in 23 languages
- Note that the figures in the following slides regard the survey respondents/results



[Full results here](#)

People living with a rare disease have difficulties with several Activities of Daily Living



impairments, activity limitations, participation restrictions

Symptoms **vary** & can be **invisible** in many ways

“One day you appear completely healthy, the next day you are sick, and two days later you appear completely normal again. Many people find it difficult to understand”

Female, Spain

“I don't look ill but am very ill with a condition which no one understands or has heard of (...)”

Female, United Kingdom



Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo. Source: [EURORDIS Photo Contest](#)

People living with a rare disease have uncovered needs regarding disability benefits

50%

28% have access to disability benefits but find that these are **not enough to cover their needs**

22% do not have access to disability benefits but find that they would need it

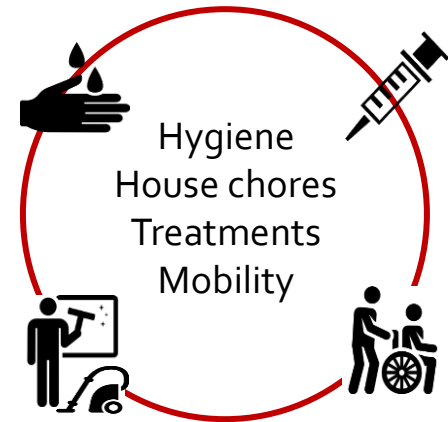
People living with a rare disease have uncovered needs regarding disability assessment

34%

of respondents submitted to disability assessment **find that the % of disability assigned to them too low**

Time burden for people living with a rare disease & carers

42% spend **more than 2h/day**
on **illness-related tasks**

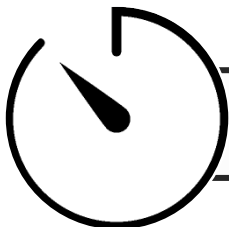


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Serious impact on quality of life of people living with a rare disease & carers



Everyday life activities



Significant time and care burden



Strong impact on work-life: absence from work, hampered professional activity, economic burden



Mental health

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

Unanimously adopted by representatives of all EU Member States (April 2016)

4. Member States (MS) should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights

Commission Expert Group Recommendations to Support Integration of RD into Social Policy

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8. RD specificities should be integrated into national systems assessing a person's level of functioning, in line with the United Nations Convention on the Rights of Persons with Disabilities



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