



## Factsheet #3: The accumulated impact of living with multiple intersectional needs.

People living with a rare disease and their families live with severe, progressive and chronic conditions and disabilities. Children, young adults and adults of all ages are impacted by rare diseases, with women being the majority among family caregivers. People living with a rare disease and their families frequently find themselves at the intersection of numerous diverse vulnerable situations, including psychosocial risks at work or school, medical uncertainties, economic hardship, discrimination and stigma.

### EURORDIS Rare Barometer Voices Survey on the impact of the COVID-19 pandemic, 2020, showed that:

- 2/3 of respondents suffered from depression and/or a feeling of not being able to overcome their problems since the beginning of the pandemic.
- 6 in 10 found the interruptions to care detrimental to their health or the health of the person they care for. 3 in 10 perceive that these interruptions to care could even probably (21%) or definitely (9%) be life-threatening.

**Quote:** “The first weeks of COVID I had fears. Suddenly there was no longer much help or contact. Some operations that should have been done have been postponed. I’m really waiting for that. I’m in a lot of pain right now. In addition, I have the feeling that I am on my own.” Person living with a rare disease.

### People in vulnerable situations

The World Health Organization (WHO) confirmed EURORDIS RBV survey results and also recognized “people with an existing health condition” as one of the main vulnerable groups who were more likely to develop symptoms of mental disorders following the pandemic, along with young people and women (WHO 2022).

The European Commission also highlights the following groups to have higher level of risks to good mental health.

- Children & Young People
- Older People
- Cancer patients and survivors
- People living with disabilities
- Chronic conditions & multi-comorbidities
- Migrant and refugee populations
- Ethnic minorities
- People from lower socio-economic backgrounds
- LGBTIQ+ people
- Women
- Victims of gender-based violence
- Victims of trafficking in human beings
- Victims of crimes
- Roma
- People living in rural or remote areas



## Conclusion:

People living with a rare disease live at the intersect of multiple communities with 'intersectional' needs and are a high-risk group that requires targeted support, resources and tailored policies to meet their specific needs.

## About Rare Diseases and EURORDIS-Rare Diseases Europe

Rare conditions are frequently chronic and highly complex. Most people with a rare condition live with disabilities which can be visible, invisible, degenerative, or vary from one day to the next. Evidence demonstrates that PLWRD and their families face serious challenges to their health, their social inclusion and their day-to-day lives, which can have a severe impact on their mental health and wellbeing.

EURORDIS-Rare Diseases Europe is a non-profit alliance of over 1000 rare condition patient organisations from 74 countries that work together to improve the lives of over 300 million people globally living with a rare condition.

The vision of EURORDIS is for a world in which each person living with a rare condition can have a longer and better life, achieving their full potential in a society that values their well-being and leaves no one behind.

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