

EXECUTIVE SUMMARY

Outline Position Paper on Mental Health & Wellbeing



A Position Paper by EURORDIS and its Members on behalf
of the rare disease community in Europe

JUNE 2024

Overview

Rare conditions impact the mental health and wellbeing of not only the affected individual but also their support network (family and friends). The majority of rare conditions present in childhood and the impact on the mental health of these children as well as their siblings and parents can be severe.

The population of people living with a rare disease (PLWRD) in the EU are in a vulnerable situation due to the accumulated impact of multiple intersectional needs – such as living with a complex condition with multiple comorbidities, living with a visible or invisible disability, being a child or adolescent, facing financial hardship, or living with stigma and discrimination. Tailored and targeted actions in all policy areas are needed to address the accumulated impact of these needs.

It is not surprising that rare conditions have an associated impact on mental health. The connection between physical and mental health is well established. Increased severity and complexity of a physical health condition in turn increases the risk to mental health and wellbeing (King’s Fund, 2012; Royal College of Psychiatrists and Centre for MH, 2013).

While this is true for both chronic conditions and rare conditions, the latter present additional difficulties that are specific to their low prevalence, highlighting the increased psychosocial vulnerability of PLWRD. Published evidence demonstrates that depression and anxiety coupled with chronic and/or rare conditions is associated with reduced quality of life and can negatively affect the course of the illness (Katon et al., 2007; Lichtman et al., 2014).

The impact of rare conditions on the mental health and wellbeing of the rare disease community has been widely recognised in global public health policy.

The United Nations General Assembly (UNGA) acknowledged the accumulated intersectional needs of PLWRD and their families in the UNGA Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families” (RES/76/132, 2021), and specifically “urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare condition, and to promote policies and programmes that enhance the well-being of their families and caregivers”.

Following the recent COVID-19 pandemic, the World Health Organization and the European Commission have identified mental health as a global public health priority, with a call for action to address this global crisis. It is therefore timely to take action to implement the UNGA call to develop psychosocial programmes for PLWRD and their families.

Recommendations

Call on the European Commission to better prevent and protect mental health problems and reduce further exclusion and marginalisation of the most vulnerable members of society, by recognising the 30M persons living with a rare condition in Europe as a population living in vulnerable situations, and taking action to address these high unmet needs.

SPECIFICALLY

- Be inclusive of all populations in vulnerable situations (including rare conditions) in the actions to implement the Comprehensive Approach to Mental Health.
- Translate the implementation of the Comprehensive Approach into a dedicated Flagship Initiative with supporting actions and adequate financial support for all vulnerable groups, including rare conditions - and improve access to psychological support.
- Allocate funding for a Mental Health & Wellbeing Toolkit for Populations in Vulnerable Situations in order to build the capacities and empowerment of these groups to become mentally healthy communities.

Call on EU Member States to honour the United Nations General Assembly Resolution's (A/RES/76/132) call for the development of effective programmes and national strategies to promote mental health and psychosocial support for persons living with a rare condition, and to coordinate EU action to develop and promote policies and programmes that enhance the wellbeing of their families and caregivers.

SPECIFICALLY

- Increase and include the visibility of mental health in the revision of Rare Disease National Plans & Strategies and commit to action to address the unmet mental health needs of PLWRD and their families.
- Integrate psychological support as an integral standard of holistic, patient-focused care, by incorporating psychosocial personnel as core members of the medical team, and through enhancing medical care to be psychologically informed.
- Recognise and support patient organisations to provide community and peer support, and access to trusted information, as the foundation of psychosocial care, enabling earlier detection and access to preventative support.
- Support new and targeted medical training to strengthen cross-specialty training, for all professionals to better understand the relationship between physical and mental health, and specifically for mental health practitioners to become more 'rare aware' and medical and nursing care practitioners to become 'mental health' aware.

The Position Paper provides a blueprint for developing psychosocial programmes (Annex I) to address the unmet mental health needs for PLWRD and their families by building on existing services and enhancing care to become psychologically informed medical care.

Annex I – Psychosocial Care

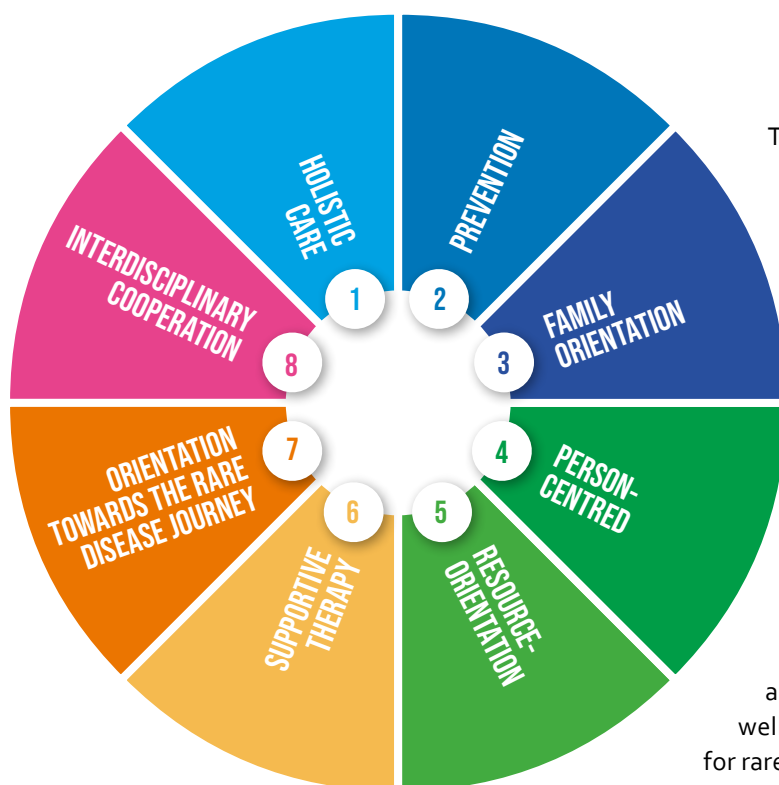
Psychosocial care is concerned with the psychological and emotional wellbeing of the patient and their family/carers, including issues around self-esteem, insights into adaption to the illness and its consequences, communication, social functioning and relationships. (Onyeka et al., 2010)

Psychosocial care is conducted in cooperation with the medical treatment team. It places the emphasis on supporting the resources of the patient and family throughout the course of the disease, during therapy, and follow-up care. It is based upon a supportive and informative relationship with the affected individual, family and social environment.

It is oriented towards the physical, emotional, social and developmental potential of the affected child or adolescent and their social environment and takes into account individual styles and abilities to cope and adjust (Schröder et al., 2008).

Psychosocial care should address the specific trajectory, social and organisational problems identified to enable families to benefit and to address and reduce the psychological stress factors associated with rare diseases.

PSYCHOSOCIAL CARE CAN BE STRUCTURED TO ADDRESS THE NEEDS FOR RARE CONDITIONS UNDER THE FOLLOWING 8 DOMAINS



The 8 domains and supporting standards are based on the PSAPOH Guideline on Psychosocial Care in Paediatric Oncology and Haematology (Schröder et al., 2008) and have been adapted to address the common needs experienced by people living a rare disease and their families.

The EURORDIS Outline Position Paper on Mental Health & Wellbeing sets out recommendations to increase the visibility of rare conditions in mental health schemes within the EU agenda and also to address mental health and wellbeing in national plans and strategies for rare conditions.

Annex II

ABOUT THIS POSITION PAPER

The co-creation process to develop this position paper started at EURORDIS Membership Meeting 2023 and continued through the engagement of EURORDIS Board of Directors, Council of National Alliances and EURORDIS Mental Health & Wellbeing Partnership Network via a series of online workshops. The position paper was developed from an evidence review of the published literature and by harnessing existing EURORDIS initiatives and various RareBarometer studies.

The recommendations relate to the European and national actions and the evidence provided in the blueprint for psychosocial care is based on the existing publications and recommendations EURORDIS submitted to the Commission's call for evidence in Q1 2023.

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This outline position paper serves as a 'holding' position and will be revised upon the completion of the population needs and results identified in EURORDIS Rare Barometer survey on mental health and wellbeing, planned from the end of 2024 to 2025.

ABOUT EURORDIS-RARE DISEASES EUROPE

EURORDIS-Rare Diseases Europe is a non-profit alliance of over 1000 rare condition patient organisations from 74 countries, including all EU countries, which 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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