



Commission Communication on 'A Comprehensive Approach to Mental Health'

Response from EURORDIS-Rare Diseases Europe

On behalf of the 30 million people living with a rare disease in Europe

June 2023

EURORDIS-Rare Diseases Europe welcomes the European Commission Communication on 'A Comprehensive Approach to Mental Health' and stresses the need for recognition of the mental wellbeing challenges specifically impacting the rare disease community. This initiative is a first and important milestone in renewing the political commitment to address the mental health needs of all Europeans.

We strongly agree with the Communication's proposal to identify high-risk groups and target support, resources and tailored policies to meet their specific 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. As such, EURORDIS welcomes the Commission's ambition to take a comprehensive approach to addressing the psychosocial and structural determinants to mental health. We also call on the Commission to ensure each of its Flagship Initiatives is implemented with an intersectional approach.

(A) Integrating Mental Health Across Policies

EURORDIS welcomes the Commission's ambition to take a comprehensive approach to addressing the psychosocial and structural determinants to mental health and calls for a coordinated and integrated approach that promotes mental health across all policies. This is truly an ambitious and innovative approach, one which requires **unified and dedicated EC-structures to oversee and guide its implementation** across the European Union.

The Communication is an important step in establishing a new, comprehensive approach to address the mental health crisis that has resulted from the significant and accumulated impact of unprecedented crises¹. However, this first step needs to be scaled up to be truly comprehensive, **coordinated under a new EU Mental Health Strategy** and supported with the development of **national plans on mental health in all policy areas** to coordinate and steer meaningful action at both European and national levels, in each EU Member State.

EURORDIS supports the call from Mental Health Organisations, along with the European Parliament Alliance on Mental Health and several other stakeholders, for the Commission to establish a dedicated internal Commission structure and to strengthen action across the European Union under a new EU Mental Health Strategy, supported by the creation of dedicated national action plans on mental health in all Member States.

¹ Including the COVID-19 pandemic, Russia's war of aggression against Ukraine, the cost-of-living-crisis and the worsening planetary crisis (climate change, biodiversity loss and pollution).



The Comprehensive Approach to Mental Health rightfully acknowledges the need to address the unmet needs of people in vulnerable situations as a key component to the success of delivering on the commitment expressed by European President Ursula von der Leyen to “take better care of each other, and for many who feel anxious and lost, appropriate, accessible and affordable support can make all the difference” on the occasion of the first announcement of the strategy during the 2022 State of the Union address.

EURORDIS urges the European Commission to be inclusive and to mainstream the needs of vulnerable groups across all Flagship Initiatives in the Communication. The Flagship Initiative to create a toolkit for a multi-disciplinary approach to mental health capacity building, for example, should be tailored to ensure the needs of all vulnerable groups (including those with rare diseases) will be addressed.

(B) Promoting Good Mental Health, Prevention & Early Intervention for Mental Health Problems

EURORDIS welcomes the commitment to increase research around improved recognition for early detection and intervention, focusing on maternal and infant health, children and adolescents, screening for vulnerable groups and brain research.

We would like to highlight that future research is also needed to enable effective screening and early detection of mental health issues in children and young people with a rare disease, especially where challenges exist in assessment due to intellectual disability and/or cognitive-behavioural problems.

The Flagship Initiative to share best practices between Member States around mental health promotion, prevention, early detection and early intervention is very much needed and welcomed, and we strongly urge that Civil Society Organisations be engaged and contribute to the development of guidance on early detection and intervention.

People living with a rare disease and their families have a *'greater risk of being disproportionately affected by stigma, discrimination and social exclusion'* and are *'disproportionally affected by poverty, discrimination and lack of decent work and employment'* (United Nations General Assembly [Resolution A/RES/76/132 2021](#)).

EURORDIS welcomes the Commission’s call for Member States to utilise EU funding opportunities and to collaborate to implement initiatives and best practices on mental health promotion and prevention, to **address the links between inequalities and mental health by increasing efforts to combat stigma and discrimination.**

EURORDIS calls on Member States to use EU funding to address “the challenges related to the prevention of mental health problems of vulnerable communities” and to pay specific attention to those in vulnerable situations, such as people living with a disability, chronic condition and/or rare disease, in order to address the links between exclusion, inequalities and discrimination. Civil Society Organisations must be engaged and contribute to the development of guidance on early detection and intervention.

(C) Boosting the Mental Health of Children & Young People

The majority of rare diseases appear in childhood and EURORDIS strongly supports the focus to address the needs of children and young people in the Communication, which is clearly justified to reduce the high rates of suicide that have been reported by UNICEF.



It is essential to remember that while the mental health burden on children with rare diseases is very high, there is also a significant impact on the parents and the family as a whole.

EURORDIS proposes that EU actions should be structured not only around the child and young person but also around the parents and siblings to improve the mental wellbeing of the whole family.

(D) Helping Those Most in Need

The new Comprehensive Approach, however, has fallen short of being inclusive of all groups in vulnerable situations, by not explicitly recognising Europeans living with existing physical health conditions, including chronic conditions and rare diseases. The lack of inclusion and visibility of the most vulnerable members of society in key EU policies will increase the risk of increase existing inequalities and further marginalising these populations.

Robust evidence exists to demonstrate the link between physical health and mental wellbeing, with a correlation between the severity and complexity of a physical medical condition and the impact on mental health and wellbeing. This is true for chronic conditions and rare diseases, with an increased psychosocial vulnerability in these populations.

We know from the previous EURORDIS Rare Barometer survey that *people affected by a rare condition face a more than three times higher risk of experiencing unhappiness and depression than that of the general population*². Moreover, a 2022 survey led by Genetic Alliance UK revealed that *over 90% of people affected by a rare condition felt anxious or depressed due to their condition, with one in five reporting suicidal thoughts*³. These findings underscore the need for greater recognition of the significant and accumulated impact on the mental wellbeing of people across our rare disease community, arising from lengthy diagnostic odysseys, limited treatment options, medical trauma and social isolation.

The mental health challenges faced by **all people living in vulnerable situations should be acknowledged in the Commission's follow up on the Communication.** This would appropriately align the initiative with the global progress being made by the World Health Organization (WHO), which has recognised the mental health vulnerabilities of individuals living with rare diseases and other physical health conditions ([WHO 2022](#)).

EURORDIS regrets that the Communication contains only two Flagship Initiatives focussing on specific vulnerable groups (victims of crime and young cancer survivors) despite clear recognition in the text the unmet needs and existence of other groups in vulnerable situations. We therefore propose that in the implementation of the Comprehensive Approach this recognition is translated into dedicated actions with adequate financial support.

EURORDIS urges the European Commission to allocate additional funding to address and improve the specific mental health needs associated with existing health conditions – chronic conditions and rare diseases – and to improve access to psychological support.

² Courbier S, et al. 2017. *Juggling care and daily life: The balancing act of the rare disease community. EURORDIS-Rare Diseases Europe's Rare Barometer Survey*

³ Spencer-Tansley R, et al. 2022 *Mental health care for rare disease in the UK - Recommendations from a quantitative survey and multi-stakeholder workshop.* Genetic Alliance UK



We also propose that a new EU action be financed by the Commission to build the capacities and empowerment of vulnerable groups to become mentally healthy communities, by developing a Mental Health & Wellbeing Toolkit for Vulnerable Populations. This toolkit could be generic in nature, identifying the best practices and evidence-based tools that could be tailored by each vulnerable population to address their specific needs.

(E) Tackling Psychosocial Risk at Work

The Communication's focus on addressing the psychosocial risks at work, which increase when an individual is living with a health condition, is welcomed by EURORDIS. The psychological impact of juggling work with multiple health appointments places undue pressure on the individual and the wider family, causing many people to have to terminate their employment, thereby increasing economic vulnerabilities.

We propose that the Communication's approaches to addressing the psychosocial risks at work also includes a focus on vulnerable populations to respond to the challenges imposed by intersectional needs, psychosocial determinants and increased risks of isolation and discrimination.

(F) Reinforcing Mental Health Systems & Improving Access to Treatment & Care

EURORDIS welcomes a key objective of the Communication: to reinforce mental health systems and improve access to treatment and care. However, a **more evenly weighted response and investment is needed in the Communication to balance both health promotion and prevention with actions to support access to quality care, treatments and support.** Currently the prevention and promotion actions overshadow the much-needed actions and investment in healthcare systems.

EURORDIS calls for the allocation of additional EU action and funding to address the needs of the 84 million people⁴ in the EU currently affected by a mental health problem, facilitating opportunities for recovery, return to school and/or employment and greater social inclusion.

The initiative for more and better trained mental health professionals to strengthen training for healthcare and other professionals is an important Flagship Initiative of the Communication, as there exist significant gaps in mental health workforces and healthcare professional skills and training in many EU Member States.

EURORDIS urges that Flagship Initiative 15 of the Communication, targeting more and better trained professionals in the EU include strengthening cross-specialty training, specifically for all professionals to better understand the relationship between physical and mental health; and for medical specialists to have increased awareness and expertise in screening, detecting and coordinating psychosocial support for people with an existing health condition.

⁴ [Health at a Glance: Europe 2018](#).



People living with a rare disease have multiple, complex, intersectional needs that increase the risk factors and psychosocial determinants that significantly impact mental health.

EURORDIS calls on the European Commission to coordinate funded actions, under a Joint Action, to strengthen and integrate psychosocial support into physical health pathways and allocate funding to support access to coordinated psychosocial support and follow-up.

(G) Breaking through Stigma

Stigma a pervasive problem both at a personal and societal level that inhibits access to care and support. The EU action to address stigma and discrimination is a critical cornerstone to all the objectives and Flagship Initiatives identified in the Communication.

EURORDIS urges the Commission to be inclusive of all vulnerable populations in Flagship Initiative 18 on tackling stigma and discrimination, to improve awareness and understanding of the mental health challenges associated with multiple intersectional needs (e.g.: living with disability, severe and debilitating health conditions) to better protect and prevent mental health problems and reduce further exclusion and marginalisation of the most vulnerable members of society.

EURORDIS requests that Civil Society Organisations be engaged in this Flagship Initiative.

(H) Fostering Mental Health Globally

EURORDIS supports the Communication's action to address the high unmet needs of people displaced from Ukraine; however other global priorities, such as supporting other refugees and migrants, warrant the development of specific Flagship Initiatives. In addition, certain global priorities delineated by the WHO and United Nations (UN) are also absent from the Communication. For example, the WHO recognises "people with an existing health condition" as one of the main vulnerable groups more likely to develop symptoms of mental disorders following the pandemic, along with young people and women ([WHO, 2022](#)).

The UN specifically underlines the high level of unmet needs and increased vulnerability of people living with a rare disease. The UN General Assembly [Resolution A/RES/76/132](#) (2021) "urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to promote policies and programmes that enhance the well-being of their families and caregivers".

EURORDIS urges the European Commission and Member States to honour the United Nations call for the development of effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to coordinate EU action to develop and promote policies and programmes that enhance the wellbeing of their families and caregivers.



(I) EU Funding for Mental Health

While there is a clear and present need to attain the collective benefits and outcomes from the existing Commission commitments and actions gathered under the Communication, there are few new initiatives and funding schemes included.

EU action to address the magnitude of the current public mental health crisis that has emerged from the accumulated impact of multiple crises must go further with more investment if the comprehensive approach truly wishes to succeed in its ambition to “bring relief to people suffering from mental health” and deliver on the three guiding principles that every EU citizen has access to adequate and effective prevention; has access to high quality and affordable mental healthcare and treatment; and is able to reintegrate in society after recovery.

EURORDIS supports Civil Society Organisations call to the Commission for a European Year on Mental Health. A European Year on Mental Health can provide a framework to support the implementation of the Comprehensive Approach, galvanising stakeholders from all sectors and boost actions and investment to increase impact for all population.

Conclusions

EURORDIS welcomes the Commission’s commitment to address mental health in all policy areas yet calls for greater inclusion of those who need help the most to successfully achieve the ambitions set out in the Communication. Without such critical inclusion, the Comprehensive Approach to Mental Health risks leaving behind many in vulnerable situations.

We appreciate the European Commission’s ambition in putting forward a strategy that addresses mental health in a comprehensive manner for the first time. However, for a truly effective response to the mental health challenges facing all of Europe’s communities, the Commission must explicitly acknowledge the mental health needs of individuals and families living with a rare disease. Specific follow-up actions must be identified and incorporated into the implementation of the Flagship Initiatives and policies identified under the Comprehensive Approach. This would enable more complete support and holistic care for those affected, complementing the Commission’s own efforts.

As the Commission moves forward, it is essential to translate the political commitment set out in this Communication into meaningful and impactful country level results, through backing the approach with strong measures, a dedicated budget and infrastructure. Our community will eagerly support the Commission’s efforts to find effective initiatives that enhance the wellbeing of Europeans, particularly those individuals living with rare diseases.

About Rare Diseases and EURORDIS-Rare Diseases Europe

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

EURORDIS’ vision is a world where all people living with a rare disease can have longer and better lives, achieving their full potential in a society that values their well-being and leaves no one behind.

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