BACKGROUND

Increased mental health risks are a reality for a range of vulnerable populations including youth, elderly, women, people with pre-existing health conditions1 (such as chronic conditions and rare diseases) or disabilities, migrants, ethnic minorities, LGBTIQA+. Without mental health promotion, prevention and support, the psychological burden and mental health co-morbidities detrimentally impact on vulnerable populations’ participation in society. The Comprehensive Approach on Mental Health needs to include all vulnerable populations and detail actions that are holistic, flexible and can be tailored to the specific needs of each population, across all policy areas.

Evidence demonstrates 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 wellbeing2. This is true for chronic conditions and rare diseases, with an increased psycho-social vulnerability in these populations. Rare diseases are complex, chronic, and often debilitating disorders with multiple intersectional unmet needs. Frequently affecting children, rare diseases lead to social exclusion and discrimination, impacting access to education and employment. The accumulative impact of living with increased co-morbidities, psychological stressors, and social inequalities results in a higher prevalence of depression and anxiety disorders.

CONCRETE ACTION

Idea: To strengthen the capacities and empowerment of vulnerable groups to become mentally healthy communities, by developing a Mental Health & Wellbeing Toolkit for Vulnerable Populations. This toolkit can be generic, identifying best practices and evidence-based tools that can be tailored by each vulnerable population to address their specific needs.

EU added value and potential benefits: Addressing the needs of vulnerable populations present an area of added value for the European Union where EU community actions help to strengthen national measures. It is reported that each vulnerable population comprise a significant sized community – young people (67 million), older people (94 million), chronic diseases (50 million) and rare diseases (30 million).

There is a large discrepancy in health and social services available across EU countries to support these vulnerable populations. The development of a Mental Health & Wellbeing Toolkit for Vulnerable Populations would help address these gaps by strengthening the capacity of patient organisations and Civil Society Organisations (CSO) with EU-shared best practices and tools to support their respective communities, reducing avoidable downstream health, social and economic costs.

How will this help to strengthen action on mental health at EU level and enhance the mental health of European citizens?

A Mental Health & Wellbeing Toolkit for Vulnerable Populations could be used by patient groups, healthcare professionals and social service providers to build knowledge and understanding of the needs of each vulnerable population and the associated impact on mental health, allowing to better target simple effective psycho-social interventions for different populations. Increasing resilience and capacities among the civil society organisations and patient groups, can support and empower them to better alleviate the risk factors and drivers of poor mental health, preventing mental health co-morbidities and addressing the high levels of unmet needs of these vulnerable populations. Specifically:

- Reducing the impact on the lives of the affected individuals and their family members, increasing social inclusion and supporting access to education, employment and independent living.

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2 The King’s fund. Long-term conditions and mental health: the cost of co-morbidities, 2012.
Strengthening the resilience and wellbeing of vulnerable populations would have a direct benefit on the economies of EU Member States by reducing downstream costs and by increasing productivity, as affected families would be better able to work and have greater independence.

A joint initiative could bring together experts and leaders from vulnerable populations to share best practices and evidence-based approaches, test their applicability and scalability and co-create a common Mental Health & Wellbeing Toolkit for Vulnerable Populations.

How will it contribute towards a comprehensive approach to mental health?

The Toolkit would:

- Draw on the existing best practice in health promotion and prevention tools to mitigate the socioeconomic and environmental determinants and associated risk factors for poor mental health.
- Use e-learning tools and materials accessible via online and downloadable by schools, employers and health and social agencies, CSOs and patient groups and communities.

Supported by psychological informed resources:

- Educational pathways and tools
- Self-care tools and coping strategies
- Family-focused psychological support tools
- Peer support and communication material
- Simple guides for early detection of drivers for poor mental health and wellbeing
- Educational factsheets and tools on the specificities of vulnerable groups
- Potential interventions to reduce the psychological impact on parents, caregivers and the wider family.

What can your organisation do to put this idea in place?

EURORDIS could support the implementation of a Mental Health & Wellbeing Toolkit for Vulnerable Populations by tailoring the resources and tools to the needs of the rare disease community.

EURORDIS could utilise the network of European federations, national alliances and individual patient and family groups and harness its various communication channels to promote a Mentally Health & Wellbeing Toolkit for Rare Diseases through our network of patient groups, during Rare Disease Day & Rare Disease Week, at EURORDIS Membership Meeting and European Conferences for Rare Diseases, to increase the accessibility and implementation of the toolkit beyond the 30 million people living with a rare disease in the EU.

**CHALLENGES**

A Mental Health & Wellbeing Toolkit for Vulnerable Populations can support actions in all policy areas specifically:

- Promotion of good mental health and prevention of mental health problems.
- Increased mental health literacy, awareness-raising & citizen empowerment.
- Early detection and screening of mental health problems.
- Strengthening the capacities of the health workforce.
- Supporting vulnerable populations and their families to self-care and to access evidence-based psycho-social interventions.
- Improving quality of life, specifically by facilitating participation in school and work by advancing on key elements such as de-stigmatisation and rights.
- Reducing and preventing of the costs in the health, social and educational system and employment sectors, due to unmanaged psychological impact.
- Enable affected individuals and families to be active in society, continuing to work, contributing taxes and living independently.

**IMPLEMENTATION**

EURORDIS could co-lead with other CSOs such as MHE and GAMIAN-Europe, EPF, EDF, UNICEF, Social Platform and its members, the co-creation of a Toolkit for Vulnerable Populations.

EURORDIS is launching a “Rare Diseases & Mental Health Partnership Network” to raise visibility, define actions and support the rare disease community to become a ‘mentally healthy community’. The Network will bring together experts who can identify best practice and evidence-based tools and co-create the Toolkit.

The Rare Barometer Survey Platform could be used to identify the specific unmet mental health needs of the rare disease community. Rare diseases could be one of the ‘use cases’ harnessed to demonstrate proof of concept that the Toolkit can be applicability, tailored and scalability to meet the specific needs of different vulnerable populations before being published.