

WHY A RESOLUTION ON PERSONS LIVING WITH A RARE DISEASE (PLWRD) AT THE UNITED NATIONS?

The impact of going through life with a rare disease goes far beyond health concerns, and affects the whole family.

The impact is felt throughout life.

Integration is difficult and/or impossible in mainstream educational systems. Parents confront difficulties finding a structure that is adapted for children with a rare disease of all ages - from kindergarten, and later in school and university.

Inequalities in terms of social inclusion and equal opportunities strike very early in life.

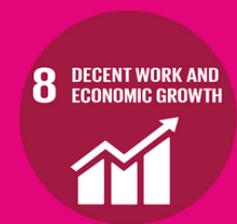


The whole family experiences impoverishment

due to increased expenses related to supporting the family member living with a rare disease, while household income decreases as parents, either stop working or reduce working hours.



As persons living with a rare disease women are disproportionately stigmatized and marginalized, and as mothers of affected children women often become the primary caregivers.



Young adults experience difficulties with every step of independent living, from finding, keeping or returning to work, to getting a loan for their life's project, having a sentimental and social life, or planning a family. Also, adapted housing that supports independence is very limited, even in wealthier countries.

Throughout their lives, PLWRD experience exclusion, discrimination, and stigmatization in addition to dealing with challenges directly related to their health, mental and physical well-being.

There is a lack of knowledge on diseases that are rare. This means that very often the community around the PLWRD cannot even put a name on the problem. **A disability with no name, no explanation and no treatment tends to increase exclusion and therefore the isolation experienced by PLWRD.**



In the context of COVID-19, the inequalities and vulnerabilities experienced by the community we represent (approximately 300 million PLWRD worldwide, and their families and loved ones) have been aggravated in every aspect.

The proposed Resolution is a holistic text that addresses all of these challenges, linked closely to the Sustainable Development Goals and the commitment to "Leave no one behind"