

Statement for Universal Health Coverage Day, 2021

A photograph of two young children, a boy and a girl, building a sandcastle on a beach. The boy, in the center, wears glasses and a yellow and blue jacket. The girl, on the left, wears a red jacket. They are both focused on their task, with their hands in the sand. The background shows the ocean and a cloudy sky.

Health Equity **The perspective of Persons Living with a Rare Disease**



RARE
DISEASES
INTERNATIONAL





Health Equity

The perspective of Persons Living with a Rare Disease (PLWRD)

Statement for Universal Health Coverage Day, 12 December 2021

As the global alliance of PLWRD and their families, Rare Diseases International (RDI) aims to promote the delivery of high-quality health and social care to everybody around the world, across all countries and across all rare diseases.

This end goal can only be achieved through Social Justice and therefore Equity. Equity is the hallmark of Social Justice because it focuses on reducing social, technological, and economic inequalities, and facilitates equal opportunity to attain the greatest level of health and well-being – Leaving No One Behind.

The 300 million PLWRD around the world and their families face inequities in all aspects of their daily lives and these have been worsened by the COVID-19 pandemic. **More attention needs to be given to Equity if we are to truly ‘Build Back Better’ and ‘Leave No One Behind’.**

Equity & Equality

Equity is a complex concept, which is often confused with Equality.

- **Equality** assumes that fairness is the provision of the same resources or opportunities, equally to everyone. It implies that “everybody must get the same” in order to achieve an equal situation.
- **Equity** is the belief that fairness requires the recognition of the different circumstances and challenges that every person faces. It implies that “everybody gets according to what everybody needs” for everyone to reach the same finish line. We may say that Equity is a way to restore Equality of outcomes, not just of chances and opportunities.



In a world where everyone faces different circumstances, “giving everyone the same” has no effect on progressing towards Social Justice and might even increase inequalities.



Equity and Recognition

The community of PLWRD and their families aims to achieve Social Justice and strive for Equity - meaning that all PLWRD, wherever they live in the world, have the same opportunity for accurate and timely diagnosis, and access to health and social care. This can only be achieved by doing more for those who have less – ‘reaching the furthest behind, first’. **Vulnerable persons living with a rare disease cumulate several layers of vulnerability, physical, social, economic, technological, which must be addressed with holistic and specific policy and action.**

UN Resolution on PLWRD

The first-ever United Nations General Assembly Resolution on PLWRD and their families, called for by RDI and its partners, recognises that PLWRD may require specific action and support to enjoy equal access to benefits and services in education, employment, and health, and to promote their full, equal, and meaningful participation in society.

It also recognises the fundamental importance of equity, social justice, and social protection mechanisms to ensure universal and equitable access to quality health and social services without financial hardship for PLWRD and their families.

Being equitable requires a deep understanding and recognition of the needs and circumstances of vulnerable persons. It requires getting a profound knowledge of the different national contexts, different social and cultural circumstances, healthcare systems, and specific barriers to access diagnosis, health and social care.

The role of RDI in Health Equity

Through its member organisations active in over 100 countries and a growing global network of rare disease stakeholders, RDI can facilitate the understanding of the challenges encountered in different national and regional circumstances and support the development of initiatives that are responsive to different contexts.

RDI can also promote a common understanding of what Equity means from the perspective of the community of PLWRD and their families within the international community. Understanding that existing frameworks do not adequately meet the specific needs of this vulnerable population, RDI advocates for rare diseases as a policy priority necessitating concerted and tailored responses.

In conclusion

If governments really aim to achieve Universal Health Coverage, ‘Leave No One Behind’ by 2030, and build inclusive societies, then the focus needs to be on Equity. Actions to achieve greater Equity should be responsive to diverse realities and multiple forms of inequalities, including the inequities experienced by vulnerable populations throughout a lifetime such as PLWRD and their families.