REDUCED INEQUALITIES

GOAL LEADERS:

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Goal description

'Systems' are not adapted to the complex needs of people living with a rare disease (PLWRD). Focusing on reducing inequalities for PLWRD involves the identification and the removal of systemic barriers through targeted policy interventions to ensure PLWRD are given the same opportunities. Focusing on reducing inequalities for PLWRD means achieving greater equity, by providing appropriate compensatory policy provisions to eliminate disadvantage and support affected individuals in reaching their maximum level of health and well-being. For this, a holistic approach that looks at the interrelated aspects of physical, mental, and social health and well-being, and that encompasses the entire life-course, is needed.

A major barrier to improving the inclusion and participation of PLWRD and their families in society is the scarcity of knowledge, limited expertise on the field and a lack of awareness of rare diseases and understanding of their impact. As a consequence, this population is psychologically, socially, culturally and economically vulnerable and faces discrimination and specific challenges in health and social care, education, employment and leisure. This, in turn, causes increased impoverishment and isolation. PLWRD can experience this at any point, or throughout, the course of life and additional factors such as gender, living in a rural area or being from a racial or ethnic minority can worsen the challenges. The COVID-19 pandemic has also had a great and disproportionate impact on PLWRD, with already ill-adapted systems being stretched even further. Our most vulnerable in society should be at the heart of any health emergency response, but instead their needs are too often traded-off and left unaddressed, resulting in life-long consequences.

Greater equity for PLWRD is prompted by the removal of these barriers. Equity is founded in cultural and societal values that are essential in order to ensure the rights of PLWRD are upheld. Equity is central to the rights to life, liberty, security of person and cuts across the whole spectrum of the pillars of our society, from education to work, offering the same opportunities for PLWRD to secure an adequate standard of living as well as to enjoy the highest attainable standard of physical and mental health. In addition, focusing on equity for PLWRD can unlock society-wide public good, benefitting not only the millions of PLWRD and their families but also bringing a productive population back into economies as well as crucial improvements in health and social care and social innovation beyond just the rare diseases field.

The complex and holistic needs of PLWRD are gaining in political recognition and support, with the unanimous approval by the United Nations' General Assembly in a new resolution aim at tackling the challenges of people living with a rare disease and their families. The new political endorsement by the UN offers the rare disease community the opportunity to target systemic change and policy development and closing the equity gap between individuals and communities once and for all!
Goal 2 of ECRD 2022 aims to explore the many opportunities to improve the recognition, understanding and knowledge of rare diseases and their impact on the people who live with them, spearheaded by policy interventions

that can address structural barriers in accessing health and social care, and empower self-determination to live life independently through access to education and work.

Track C & D Session 1 sets the framework to navigate the following two topic-based sessions. It considers how rare diseases are invisible in ill-adapted health care and social systems and addresses the preconditions for inclusions and equal opportunities for PLWRD.

Track C Session 2 explores how greater integration of health and social care unlocks better access to health and social care for people living with a rare disease.
Track D Session 2 shows the everyday challenges for a PLWRD to access education and employment while sharing good practices of inclusivity at school and work which trigger individuals' greater independence and contribution to society.

Across all Sessions, case studies will be presented whereas panel discussions will formulate policy solutions.

Track C/D Session 1: Wednesday 29 June 2022, 14:00 – 16:00 CET

Invisibility as a roadblock towards reducing inequalities for people living with a rare disease.

People living with rare diseases (PLWRD) are invisible in ill-adapted systems due to the lack of knowledge, recognition and understanding on rare diseases and their impacts on all aspects of life. Inequalities in health-social care, education and work are majorly due to the lack of adaptation to the needs of this population. The greater the complexity, the greater the need for the service-system-society to adapt, and this depends on a combination of awareness, knowledge, willingness as well as tools and practices that empower positive action.

Inequalities experienced by PLWRD can be made visible through disability assessment, at an individual level, and by measuring the burden of rare diseases, at a population level. However, methodologies and practices do not always capture and recognise the complex needs of PLWRD, consequently limiting access to benefits, social protection, and reasonable accommodation.

This session sets the framework to navigate the following two topic-based sessions within Goal 2 of the programme. With the premise that visibility is a pre-condition for inclusion of PLWRD in society, it outlines the evidence and data needed to measure the burden of rare diseases to make them more visible and to inform policy decisions. The session also outlines the infrastructural, technological and policy shifts and tools that support systems to adapt to the needs of PLWRD, and that favour inclusion and equal opportunities in society (policy frameworks like for instance, the European Pillar of Social Rights or the Disability Strategy).

Chaired by:
Dr Ana Rath, Director, Orphanet.

Speakers:
Dr Juanita Haagsma, Assistant Professor, Erasmus Medical Centre Rotterdam
Dr Androulla Eleftheriou, Executive Director, Thalassaemia International Federation
Dr Ana Rath, Director, Orphanet
Flaminia Macchia, Executive Director, Rare Diseases International
Inmaculada Placencia Porrero, Senior Expert, European Commission - DG Employment, Social Affairs & Inclusion

Alba Ancochea, Chief Executive Officer, FEDER (Federacion Espanola de Enfermedades Raras)
Dr Anne-Sophie Lapointe, Head of Rare Diseases Project, French Ministry of Health and Solidarity

Track C Session 2: Wednesday 29 June 2022, 16:30- 18:00 CET

Inequalities in accessing health and social care for people living with a rare disease.

People living with a rare disease need medical care and follow-up support from different categories of health professionals, often from several different medical specialties, as well as from social workers and other social and local service providers. However, people living with a rare disease face fragmented care pathways and mainstream services that are not flexible enough to take into consideration unprecedented needs.

Health and social care services are not constructed in a way to meet the needs of complex diseases and development disorders. Services have structural barriers to access services leading to vulnerable individuals falling through the gaps in health and social care systems. Complexity of the rare disease means that patient health needs cut across disciplines and there is a lack of multidisciplinarity (or multidisciplinary teams) working (in reality) and a lack of holistic care. Greater integration of health and social care has been shown to directly reduce these inequalities.

Health inequalities show a significant discrepancy across Europe with a dramatic variation in survival rates due to accessing trained, experienced medical team. These inequalities can disproportionately affect rural populations due to limited access to services and further compounded by the lack of willingness to accept a PLWRD in everyday life. Clinical networks and tele-expertise have started to test how to reduce crossborder inequalities.

Chaired by:
Maria Montefusco, Board of Directors, EURORDIS-Rare Diseases Europe

Speakers:
Dr Julia Faulkner, Patient Advocate, Tracheo-Oesophageal Fistula Support (TOFS) UK and EAT
Encarna Guillén- Navarro, Hospital Clinico Universitario Virgen De La Arrixaca, Unit for Medical Genetics
Tony Holland, President, International Prader-Wili Syndrome Organisation (IPWSO)
Dorica Dan, President, Romanian National Alliance for Rare Diseases (RONARD) and Board of Directors member, EURORDIS
Isabella Brambilla, Member and President, Dravet Italia Onlus
Prof. Wout Feitz, ERN eUROGEN HCP Network Coordinator
Andreas D. Rosenberger, Centre Leader, National Neuromuscular Centre, Norway

Track D Session 2: Wednesday 29 June 2022, 16:30 – 18:00 CET

Inequalities in accessing education, work and independent living for people living with a rare disease.

To have the same opportunities for economic and social independence, access employment is predicated on acquiring the necessary skills and abilities from school and the education system. Educational systems and schools are not always effective in responding and adapting to the physical and emotional health needs of someone with a complex rare disease, without creating equalities for the individual in accessing the same opportunities in social and educational activities as others. Even with a solid education and having the capacity and desire to work, people living with a rare disease have can face serious stigma and discrimination leading to increased challenges to access employment or returning to work following treatment. This is also the case of their carers who need support to fulfil their caring role whilst remaining in employment.

This session will explore the everyday challenges for a PLWRD to access education and employment and sharing good practice of how schools and business can be inclusive and offer an individual with the same opportunities to contribute to society and be independent. Many PLWRD experiencing the disability gap widening and increased social isolation and stigma in adulthood. The session will also explore societal normal and public perceptions influence inclusion in employment and society, sharing good practice to inform a policy discussion.

Chaired by:
Matt Bolz-Johnson, ERN & Healthcare Advisor, EURORDIS-Rare Diseases Europe.

Speakers:
Allison Watson, Chief Executive Officer and Cofounder, Ring20,
Oscar Raul Lozano, University of Valencia
Verity Fisher, Physiotherapy Manager, National Star
Jamie Bolling, Research Developer, Swedish Disability Federation
Petia Stratieva, Retina International
Loredana Dicsi, Membership, Internal Communication & Youth Officer, European Disability Forum