

IFSW European Conference 2017 Iceland - Abstract for Platform Presentation

Title: Empowering Partnerships: Putting people with a rare disease 'in the driving seat'

Presenters:

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This presentation will highlight the achievements of a dynamic partnership between the European Region of the International Federation of Social Workers (IFSW) and the European Organisation for Rare Diseases (EURORDIS) which aims to equip social services staff with the knowledge and skills necessary to assess the impact of a Rare Disease (RD) on an individual's well-being and lifestyle and design and deliver services that enable them and their family to enjoy a good quality of life.

A disease is defined as rare when it affects no more than 5 in 10,000 people and there are 5,000 to 8,000 distinct RD's in the European Union (EU). Currently no treatment is available for many of these conditions and a significant hereditary factor must also be considered.

EURORDIS is a service user driven alliance of organisations and individuals active in the field of RD's. The objectives of EURORDIS are to build a strong Pan-European community of people living with RD's, to be this community's voice at the European level and directly or indirectly to fight against the impact of RD's by improving access to information, services, diagnosis, treatment and care and by promoting research and the exchange of good practices.

Founded in 1997 and supported by its members and by AFM-Telethon, the European Commission, corporate foundations and the health and pharmaceutical industry, EURORDIS represents 633 patient organisations in 59 countries providing a voice to the approximately 30 million people living with RD's in Europe alone. Ensuring the effective exchange of information about particular RD's, available treatment and appropriate models of care is of course a global issue and this presentation will highlight important recent developments at a UN level which members of the EURORDIS network are currently spearheading.

IFSW Europe's partnership with EURORDIS seeks to raise awareness amongst social services providers of the importance of front line staff being able to access experts and secure up to date information when they are supporting people suffering from RD's. Stressing the need for investment in training that empowers sufferers, their families and professionals to work together to overcome challenges arising from their illness, IFSW Europe and EURORDIS emphasise the importance of user engagement in the design and delivery of training to create effective awareness and improve the capacity of the professionals to provide person centred services.

This issue is now firmly on the EU agenda ([EU Joint Action on Rare Diseases \(EJA\)](#)) and each Member State is required to have a Strategic Plan in place for the development of services for people with RD's. The presentation will include information about plans already in place and those countries that have yet to publish their proposals. The presenters contributed to the formulation of a policy document entitled '[Guiding Principles on Training for Social Services Providers](#)' addressed to the European Commission, Member States and all stakeholders.

Joint workshops were held last year at International Social Work Conferences in Helsinki and Edinburgh by IFSW Europe and colleagues from EURORDIS who work in specialised resource centres for RD's in Norway and Romania. The presentation will include examples of some of the innovative activities carried out in these settings. Many more such centres are required across Europe to provide in-house and outreach information and training for people suffering from RD's, their carers and the many professionals from a wide range of disciplines supporting them in local communities.

Without up to date information, individually designed integrated health and social care and adaptations, people with (RD's) will continue to be even more disadvantaged and marginalized than those suffering from more prevalent forms of illness and disability.

The presentation will highlight the following key issues for social services personnel:

- Ownership of information and processes must rest with the individual suffering from a RD
- Person centred care requires a different mindset.
- The need to put our knowledge and skills at the disposal of the person with a RD and their family or other carers and pursue an agenda set by them.
- The requirement to provide non-directive assistance to people with RD's to assess, minimise and manage risks and conflicts of interest associated with their illness, except when serious risk to their health or wellbeing necessitates a more prescriptive approach.
- The necessity to ensure that people affected by rare diseases are made aware of services and sources of support and assisted to challenge decisions adversely affecting the care and support they are receiving.

CM/IHJ