



RESOURCE CENTRES FOR RARE DISEASES



Actions performed by Resource Centres (RC) are generally specifically targeted to people living with rare diseases (PLWRD). These centres often function in partnership or cooperation with Centres of Expertise or constitute part of a Centre of Expertise themselves.

Resource Centre services include information and guidance services, training courses, provision of information concerning social benefits, and documentation and research services. Daily support therapies, medical/psychological consultations and therapeutic recreation activities are often also provided by these centres. Resource Centres could be defined as a 'one-stop shop style' service for rare disorders.

WHY ARE RESOURCE CENTRES NEEDED?

Several studies and documents have recognised the need for Specialised Social Services [which include RC], both at European and National levels.

The European Commission's Communication on Rare Diseases: Europe's Challenges¹ specifically mentions Specialised Social Services in its article addressing the «Access to Specialised Social Services» and their importance for PLWRD. The Communication further states that these services «need to be sustainable to pursue their goals: awareness-raising, exchange of best practices and standards, pooling resources using Health Programme and Disability Action Plans».

The European Project for Rare Diseases National Plans Development (EUROPLAN) guidance document², developed by partners and experts, mentions that «Specialised Social Services [including RC] are instrumental to the empowerment of PLWRD and improve well-being and health. For people living with a rare, chronic and debilitating disease, care should not be restricted to medical and paramedical aspects, but should also take into account social inclusion and psychological or educational development».

The final report of EUROPLAN, based on 15 National Conferences organised in 2010-2011, states that «Specialised Social Services are a support for people living with a chronically debilitating rare disease and their family carers» and «mechanisms need to be devised to recognise

and integrate PLWRD into existing social services (rehabilitation, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs» (R6.5)³.

WHY ARE RESOURCE CENTRES IMPORTANT?

Resource Centres fit the description of the 'one-stop shop style' service for RDs referred to by the participants in the RehabCare Study "An investigation into the social support needs of families who experience rare disorders on the island of Ireland" by being able to provide «flexibility and person-centred approaches which fit the service around the individual's specific needs» (McGarvey and Hart, 2009)⁴.

These centres commonly create a bridge between PLWRD/families and all the stakeholders involved in patient care, such as medical services, rehabilitation and therapeutic services, social services and social support authorities, education professionals and other professionals directly working with PLWRD.

1 - Communication from the Commission on Rare Diseases: Europe's Challenges: http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf [accessed 16 April 2013].

2 - Recommendations for the Development of National Plans for Rare Diseases: Guidance Document: http://download.eurordis.org/europlan/2_EUROPLAN_Guidance_Documents_for_the_National_Conference/2_EUROPLAN_Recommendations_for_Rare_Disease_National_Plans_Final.pdf [accessed 16 April 2013].

3 - Main Results of the 15 EUROPLAN National Conferences: Final Report: <http://download.eurordis.org/s3.amazonaws.com/rdpolicy/final-report-europlan-15-national-conferences.pdf> [accessed 16 April 2013].

4 - McGarvey, B. and Hart, C., 2009. An Investigation into the social support needs of families who experience rare disorders on the island of Ireland. Dublin: RehabCare.

Resource Centres provide guidance and support to PLWRD who need assistance to obtain social benefits or to get their social rights recognised, and offer social empowerment on different levels. Additionally, these centres provide training, guidance and information to different carers, including not only relatives but also social services providers and special education teachers. By serving all these groups, RC have an essential role in the improvement of the global social care of PLWRD.

Resource Centres are also essential in handling rare complex cases. These services can coordinate with complex case managers located at other regional or national services, assuring proximity support to PLWRD and their families. RC can also be considered complementary to medical services, helping to fulfil the multidisciplinary mission of Centres of Expertise, as suggested by the European Commission's Communication on Rare Diseases: Europe's Challenges.

HOW TO ADDRESS THE ISSUE?

The role of National Plans and of the EUCERD Joint Action

The 25 EUROPLAN National Conferences scheduled for 2012-2015 within European Union Committee of Experts on Rare Diseases (EUCERD) Joint Action: Working for Rare Diseases⁵, include the theme of Specialised Social Services [which include RC] and social policies into the outline of the conference programmes, in order to motivate discussions, preferably involving the national, regional and local competent authorities.

Furthermore, as National Plans are being drafted, commented and approved, there is a higher chance of addressing the social challenges of PLWRD through existing social policies and through the development of Specialised Social Services in the National Plan. EURORDIS therefore advises all advocates to strive for the inclusion of a representative from authorities competent for social policies and services in the National Plan work group, as a starting point. The drafting group shall also be encouraged to guarantee that social policies and Specialised Social Services are not only mentioned in the National Plan but also assigned a corresponding budget allowing for the development and sustainability of the proposed measures.

Patient advocates expect as well that the EUCERD Joint Action's Work Package 6, led by EURORDIS, dedicated to "Specialised Social Services and Integration of Rare Diseases into Social Policies and Services"⁶, can serve as an awareness raiser and as a motor of exchange of experiences among countries. The project brings visibility to existing services and will encourage the sharing of information on good practices, quality services and different sustainability and governance methods, increasing the chances of success of existing and future Specialised Social Services and social policies for PLWRD.



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RELATED ISSUES

Recognising the specific social challenges of PLWRD

The social needs of PLWRD are not always necessarily covered by existing general social services and policies, including disability policies and services, due to the specificity of RDs: rare number of cases – hence not easily recognised, identified, visible or associated with lacking functionalities – complex, with multiple clinical expressions, generating multiple disabilities. These specificities require a special adaptation of the services provided or, at minimum, adapted information and training of social services providers.

The current challenge for PLWRD is to get their needs recognised and met within existing social services and frameworks in their countries/regions.

The focus of the present advocacy actions shall not necessarily be the installation of completely new RC specific to RDs, but rather the optimisation of existing resources in order to facilitate access of PLWRD to the vast set of services provided by Resource Centres.

Needs assessment and reflection on the implementation of RC specifically addressing RDs is encouraged, within the framework of the development of Centres of Expertise, providing multidisciplinary care to PLWRD and gathering expertise that should be available to local medical and social care providers.

The focus also relies on ensuring that the RC themselves can be provided with access to guidelines and good practices facilitating the work of their service providers when integrating PLWRD, providing valuable tools to existing RC as well as to new services. On this matter, a document has been produced, in the scope of the EUCERD Joint-Action workshop on Guiding Principles for Specialised Social Services (Romania, December 2012) containing 10 good practices for the implementation and management of these services⁷.

REFERENCES AND ADDITIONAL INFORMATION

- EURORDIS Paper "Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies"
<http://www.eurordis.org/sites/default/files/paper-social-policies-services-eja-wp6.pdf>
- Guiding Principles for Specialised Social Services - EUCERD Joint Action Document
<http://www.eurordis.org/sites/default/files/EJA-WP6-Guiding-Principles-Specialised-Social-Services.pdf>
- EURORDIS Website Section on Specialised Social Services, Resource Centres
<http://www.eurordis.org/specialised-social-services#rc>
- EURORDIS EUROPLAN Website Section
<http://www.eurordis.org/eu-rare-disease-policy#tabs-2>
- EUCERD Joint Action Website Section
http://www.eucerd.eu/?page_id=304

⁵ The EUROPLAN Project: http://www.eurordis.org/content/europlan-project#europlan_II [accessed 16 April 2013].

⁶ EUCERD Joint Action: Working for Rare Diseases, Work Package 6: http://www.eucerd.eu/?page_id=304 [accessed 16 April 2013].

⁷ Guiding Principles for Specialised Social Services: <http://www.eurordis.org/sites/default/files/EJA-WP6-Guiding-Principles-Specialised-Social-Services.pdf> [accessed 7 May 2013].



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