



RESPITE CARE SERVICES FOR RARE DISEASES



EURORDIS
Rare Diseases Europe

Respite care is provided, on a short term basis, for people living with rare diseases (PLWRD), so that their carers can have a short relief from care giving. Respite Care Services (RCS) can be offered in various ways:

- Residential: the person living with the RD attends an adapted centre to be looked after by a "respite care family";
- Domiciliary care: some services provide a caregiver who comes to the family home, and takes over care giving duties so that the regular carer can have rest from the daily routine of care giving;
- Day care: day care centres, nursing homes, institutions or respite group homes with assisted living facilities (no overnight facilities);
- Emergency: services that give access to respite on a short notice in the event of an unexpected emergency.

WHY ARE RESPITE CARE SERVICES NEEDED?

Several studies and documents have recognised the need for RCS, both at European and National levels.

The European Commission's Communication on Rare Diseases: Europe's Challenges¹ specifically mentions Respite Care Services in its article addressing the «Access to Specialised Social Services» and their importance for PLWRD. The Communication further states that RCS «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 EUROPLAN guidance document for the National Plans², developed by partners and experts, mentions that «Specialised Social Services [including RCS] 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 only 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 the 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 RESPITE CARE SERVICES IMPORTANT?

Respite care enables the caregivers to maintain the ability to continue care giving. The benefits to carers described in the literature fall into these two broad categories: stress reduction and self-esteem increase; improved family functioning (Merriman and Canavan, 2007)⁴.

A second purpose of RCS is to make it possible for PLWRD to live according to their usual daily routine and to provide a place to experience and perform recreational and meaningful activities away from their parents/caregivers. Benefits to service users mentioned in literature are socialisation, and enjoyment of experiences outside the home (Merriman and Canavan, 2007)⁴.

1 - Communication from the Commission on Rare Diseases: Europe's Challenges: http://ec.europa.eu/health/ph_threats/inon_com/docs/rare_com_en.pdf [accessed 23 November 2012].

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 23 November 2012].

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 23 November 2012].

4 - Merriman, B. and Canavan, J., 2007. Towards best practice in the provision of respite services for people with intellectual disabilities and autism. HSE/NUI, Galway Child and Family Research Centre. <http://www.npsa.ie/Documents/RespiteResearch/respiteresearch.pdf> [accessed 29 July 2012].

Without respite, not only can families suffer economically and emotionally, but also caregivers themselves may face serious health and social risks as a result of stress and exhaustion associated with continuous care giving.

The long term implications of providing respite care include benefits for both carers and PLWRD. The families will become better carers because of the relief respite provides and due to the exchange of experience with respite care providers while PLWRD will increase their life quality. Respite often prepares PLWRD to live more independently in the present but also as grown-ups. In this way, the quality of the overall care provided will improve.

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 RCS] 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.

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 attended, 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 RCS specific to RDs, but rather the optimisation of existing resources in order to facilitate access of PLWRD to existing RCS where they can be integrated – such as, for example, services for people with disabilities. Further needs assessment and reflection on RCS specifically addressing RDs is encouraged.

The focus shall also rely on ensuring that the RCS themselves can access guidelines and good practices facilitating the work of the social services providers when integrating PLWRD, providing valuable tools to existing Specialised Social Services 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, Respite Care Programmes
<http://www.eurordis.org/specialised-social-services/#rsc>
- EURORDIS EUROPLAN Website Section
<http://www.eurordis.org/eu-rare-disease-policy>
- 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 23 November 2012].

⁶ - EUCERD Joint Action "Working for Rare Diseases", Work Package 6: http://www.eucerd.eu/?page_id=304 [accessed 23 November 2012].

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].

