



THERAPEUTIC RECREATION PROGRAMMES FOR RARE DISEASES



EURORDIS
Rare Diseases Europe

Therapeutic Recreation Programmes (TRP) are any organised recreation activity (summer camp, ad hoc trip) which gives people living with rare diseases (PLWRD) the possibility to take a break from focusing on their disease and treatment to concentrating on fun and leisure. TRP can also focus on different empowerment and disease/symptom management activities. There are three main formats of TRP:

- 'Single illness' TRP: for people living with a specific condition, or their siblings;
- 'Mixed illness' TRP: for people living with a variety of conditions and/or their siblings/spouses;
- 'Mainstream or integrated' TRP: for people living with a variety of conditions, siblings/spouses, and people not affected by any illness.

WHY ARE THERAPEUTIC RECREATION PROGRAMMES NEEDED?

Several studies and documents have recognised the need for TRP, 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 TRP «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 TRP] are instrumental to the empowerment of PLWRD and improve wellbeing 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 THERAPEUTIC RECREATION PROGRAMMES IMPORTANT?

Leisure and recreational activities will help PLWRD gain self-confidence and feel empowered to deal with everyday challenges. Ultimately, PLWRD and their close ones need time off. They need to spend some days in an environment where they can stop thinking about their disease, where they can meet, socialise and play with other PLWRD. TRP allow patients with RDs and their families to meet these needs in a safe, friendly and well-adapted environment.

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 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].

The study "Outcomes associated with participation in a therapeutic recreation camping programme for children from 15 European countries: Data from the Barretstown Studies" mentions that «benefits were noted in their [patients'] experience of physical symptoms, affect pertaining to physiological hyperarousal and quality of life in the short and longer term. Positive changes were also noted in relation to self-esteem as it pertains to global self-worth and physical attractiveness». The study then concluded that «these findings clarify previous research and suggest that camping programmes have an important role to play as a complementary intervention in facilitating adjustment to chronic illness» (Kiernan, Gormley and MacLachlan, 2004)⁴.

TRP extreme importance for siblings has also been already reported. Siblings tend to share common difficulties which include a lack of understanding and knowledge about their brother or sister's disorder, also the feeling of being left out and potential embarrassment at their brother or sister looking and behaving differently (McGarvey and Hart, 2009)⁵.

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 Diseases⁶, include the theme of Specialised Social Services [which include TRP] 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"⁷, 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 TRP services specific to RDs, but rather the optimisation of existing resources in order to facilitate access of PLWRD to existing TRP where they can be integrated – such as, for example, services for people with disabilities. Further needs assessment and reflection on TRP specifically addressing RDs is encouraged.

The focus shall also rely on ensuring that the TRP themselves can access guidelines and good practices facilitating the work of the social services providers when integrating PLWRD, providing valuable tools to existing TRP 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 services⁸.

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, Therapeutic Recreation Programmes
<http://www.eurordis.org/specialised-social-services/#trp>
- EURORDIS EUROPLAN Website Section
<http://www.eurordis.org/eu-rare-disease-policy>
- EUCERD Joint Action Website Section
http://www.eucerd.eu/?page_id=304

4 - Kiernan, G., Gormley, M. and MacLachlan, M., 2004. Outcomes associated with participation in a therapeutic recreation camping programme for children from 15 European countries: Data from the 'Barretstown Studies'. *Social Science & Medicine* (1982), Sep;59(5):903-13.

5 - 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.

6 - The EUROPLAN Project: http://www.eurordis.org/content/europlan-project#europlan_II [accessed 23 November 2012].

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

8 - 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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