



ADAPTED HOUSING SERVICES FOR RARE DISEASES



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Rare Diseases Europe

Adapted Housing Services (AHS) represent a particular type of service, often associated with multiple disabilities. Sometimes called 'therapeutic apartments', these services allow people living with rare diseases (PLWRD) to develop and enjoy some level of autonomy by living within the comfort of their own home, alone or with peers, assisted by supportive staff, rather than being placed in an institution.

Adapted Housing Services might also refer to a specific local/regional grant awarded to the patient and/or family in order to pay for any house adaptation work, to prevent families from having to move into other facilities, or with the purpose of adjusting regular buildings to certain specific needs (wheelchair, small size, hearing disabilities, autistic spectrum disorders, etc.).

WHY ARE ADAPTED HOUSING SERVICES NEEDED?

Several studies and documents have recognised the need for Specialised Social Services [which include AHS], 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 AHS] 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 ADAPTED HOUSING SERVICES IMPORTANT?

Adapted Housing Services make it possible for PLWRD to live as independently as possible, while being monitored by supportive staff habilitated to provide assistance for any daily routine activities that cannot be performed independently.

People living with rare diseases can thus enjoy a high level of independence and autonomy, while being integrated into a community of peers without jeopardising their safety nor their clinical and therapeutic needs.

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/rpdpolicy/final-report-europlan-15-national-conferences.pdf> [accessed 16 April 2013].

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 Diseases⁴, include the theme of Specialised Social Services [which include AHS] 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"⁵, 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 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 Adapted Housing Services specific to RDs, but rather the optimisation of existing resources in order to facilitate access of PLWRD to existing AHS where they can be integrated after serviced adaptation – such as, for example, group homes for people with disabilities. Further needs assessment and reflection on AHS specifically addressing RDs is encouraged.

The focus also relies on ensuring that the AHS themselves can be provided with access to guidelines and good practices facilitating the work of the group home supporting staff when integrating PLWRD, providing valuable tools to existing AHS 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 services⁶.

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, Adapted Housing
<http://www.eurordis.org/specialised-social-services/#ah>
- EURORDIS EUROPLAN Website Section
<http://www.eurordis.org/eu-rare-disease-policy/#abs-2>
- EUCERD Joint Action Website Section
http://www.eucerd.eu/?page_id=304

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

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

6 - 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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