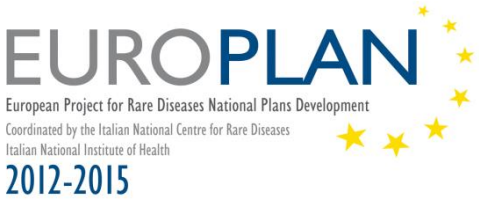

EUROPLAN NATIONAL CONFERENCES 2012-2015

CONTENT GUIDELINES FOR WORKSHOP 6 / THEME 6

SOCIAL SERVICES FOR RARE DISEASES

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A. How to read and use these Content Guidelines

The EUROPLAN Content Guidelines cover 6 main Themes. For each Theme, these Content Guidelines cover all the core topics to be addressed in the Workshop dedicated to that Theme. These Guidelines include:

1st column – RESOURCES **This column includes the background documents and relevant material that should be referred to in preparation for the discussion**. They mainly include: • Specific articles of the EU Council Recommendation on an action in the field of rare diseases; • Specific items of the Commission Communication on Rare Diseases: Europe's challenges; • Specific recommendations from the "EUROPLAN Recommendations"; • Extracts from the Synthesis Report of the 15 EUROPLAN National Conferences held in 2010; • EURORDIS Paper: Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies; • EUCERD Core Indicators; • EUROPLAN Indicators. **NB: Full documents of the sources referenced above can be found in Section C**	**2nd column - TOPICS FOR DISCUSSION** **The topics for discussion are questions formulated to stimulate the discussion within the Workshop**. The conference organisers, with the help of their Advisor, will **select those questions that are relevant for the discussion in their countries**. As such, **not all listed questions need to be addressed in a mandatory way**. They rather represent a "menu" from which to pick the questions that address the most relevant topics in the country, having considered the level of advancement of the national policy on rare diseases in the country.

B. Guidelines for discussion for Workshop 6 - Theme: Social Services for Rare Diseases

RESOURCES	TOPICS for DISCUSSION
B.1. Social resources for people with disabilities	
"The Voice of 12,000 Patients" (Experiences and Expectations of Rare Disease Patients on Diagnosis and Care in Europe) http://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLBOOKr.pdf (page 22) "Services required by rare disease patients are often inadequately available and unadapted due to the fact that they are not covered by their respective healthcare systems (i.e. psychotherapy, occupational therapy, dental care, optics, nutrition). This is especially true for social services. Social security systems are usually designed around common diseases and are not flexible enough to take into consideration unprecedented health needs. This is also true for adjusting reimbursements." **Final Report of EUROPLAN I Conferences** (Area 6, pages 55) "In a number of countries existing programmes are unevenly distributed, not appropriate because either not targeted to RD, old fashioned or hardly accessible due to the bureaucratic hurdles necessary to receive an official acknowledgement. • Mechanisms need to be devised to recognise and integrate RD patients into existing social services (habilitation, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs. For instance, in order to address the specific evaluation of disability in RD patients, it is important modifying the disability evaluation procedures to consider other factors apart from the functional character of the disorder, such as its chronic character, degenerative processes, behavioural aspects and outbreaks. • It is important that NPs include such provisions and envisage concrete actions to	• What national social security schemes support families and patients with disabilities? • How are existing social resources mapped at national level? Is there an official directory of social resources for people with disabilities? • One of the findings of the EURORDIS publication "The voice of 12,000 Patients" was that «social security systems are usually designed around common diseases and are not flexible enough to take into consideration unprecedented health needs». Considering the national schemes supporting people with disabilities, the way disability is detected and assessed so to trigger the entitlement to measures of public support, how do rare diseases "perform"? How "visible" are they? • In other words, **what mechanisms do support the take-up of social security benefits by people living with rare diseases**? Please see the suggestion from *Final Report of the EUROPLAN I conferences (see column on the left):* "It is important modifying the disability evaluation procedures to consider other factors apart from the functional character of the disorder, such as its chronic character, degenerative processes, behavioural aspects and outbreaks."

turn them into reality. For instance, improving the legal framework could be part of the solution to speed up procedures. Financial support for such services to ensure their long-term sustainability is also requested, as well as ad hoc training for staff involved in the care of RD patients." (Area 6, page 56) • "In order to overcome the fact the RD are often "invisible" to social services, it would be beneficial for RD patients to design for them consistent, validated and evidence based healthcare pathways (see Area 4), covering a spectrum of conditions and symptoms. This would be particularly beneficial for those with a progressive or chronic condition. Coordinating information and outlining what a "good" pathway should look like could help to provide a more consistent service across the country, thus potentially decreasing the disparity of services that patients and families currently receive."	
B.2. Specialised social services for rare diseases	
Council Recommendation I. PLANS AND STRATEGIES IN THE FIELD OF RARE DISEASES 1. Establish and implement plans or strategies for rare diseases at the appropriate level or explore appropriate measures for rare diseases in other public health strategies, in order to aim to ensure that patients with rare diseases have access to high-quality care, including diagnostics, treatments, habilitation for those living with the disease and, if possible, effective orphan drugs, and in particular: (a) elaborate and adopt a plan or strategy as soon as possible, preferably by the end of 2013 at the latest, aimed at guiding and structuring relevant actions in the field of rare diseases within the framework of their health and social systems; **Commission Communication on RD** 5.2. Access to specialised social services Centres of expertise may also have an essential role in developing or facilitating specialised social services which will improve the quality of life of people living with a rare disease. Help Lines, Respite Care Services and Therapeutic Recreation Programmes, have been supported and need to be sustainable to pursue their goals: awareness-raising,	• What actions of the national plan or strategy on rare diseases are or will be aimed at "guiding and structuring relevant actions in the field of rare diseases within the framework of …the social systems?" (*Council Recommendation, I, 1.a*, see *left column of this document*) • What role do **Centres of Expertise** have in developing or facilitating specialised social services aimed to improve the quality of life of people living with a rare disease? • How are existing social resources for people living with rare diseases mapped at national level? Is there an official **directory of social resources specifically for people with rare diseases**? • In particular: what national schemes do exist that promote access of people living with RD and their families to : – Respite Care Services – Therapeutic Recreational Programmes – Adapted housing

exchange of best practices and standards, pooling resources using Health Programme and the Disability Action Plans. **EUROPLAN Recommendations** R 6.5 Specialised social services are supported for people living with a chronically debilitating rare disease and their family carers. R 6.7 A directory of centres providing specialised social services, including those offered by patients' associations, is compiled, kept updated and communicated to national, regional and patients' websites and included in the Rapsody network*. R 6.8 Interactive information and support services for patients are promoted (such as help lines, e-tools etc). R 6.9 Information and education material is developed for specific professional groups dealing with rare diseases patients (e.g. teachers, social workers, etc.). 90. Specialised social services are instrumental to the empowerment of people living with rare diseases 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. Online communities are vital for establishing contacts among extremely isolated patients. Therapeutic Recreation Programmes encourage personal development. Respite Care Services give family members and carers downtime opportunities. *(the most recent definitions have being developed in Work Package 6 of the EUCERD Joint Action on Rare Diseases of which the EUROPLAN conferences are a component. Please see at the end -section B.6- the definitions from the Paper.)* * The Rare Disease Patient Solidarity project - RAPSODY - co-funded under the EU Public Health Programme, was run by EURORDIS and served to create an online listing of European services aimed at improving the lives of rare disease patient.	– Resource Centres (For the definition of each type of service, please go to section C.5 of this document) • What level and sources of **information** do patients with rare diseases have on existing social resources? In particular, is there any specific information path that people living with rare diseases could use to find their way through existing legislation and schemes? • What **ad hoc training** modules or initiatives are envisaged for providers of social services and care to people living with rare diseases? • How are specialised social services for rare diseases funded? Is there a specific fund to support the **long-term sustainability** of such measures? • How are specialised social services for people living with rare diseases **evaluated**? What **quality systems** are adopted or guidelines followed to ensure an adequate level of service provision?
B.3. Policies to integrate people living with rare diseases into daily life	
EUROPLAN Recommendations R 6.6 Specialised social services are established to facilitate integration of patients at schools and workplaces.	• What national schemes do exist that promote the integration of people living with rare diseases in their daily life (school, worklife, etc.) • Specifically, what of the following measures do exist and which ones need to be

93. Examples of social services to integrate patients in their daily life and support their psychological and educational development are:
a) educational support for patients, relatives and caregivers;
b) individual support at school at different schooling level, for both pupils with rare diseases and teachers, including disease-specific good practices;
c) promotional activities aimed to foster higher education for people with rare diseases;
d) supporting mechanisms to enter and stay in school and participate in work life for people with disabilities.

Final Report of EUROPLAN I Conferences
(Area 6, pages 55)

"This Recommendation hints to the need of patients living with rare conditions to integrate into social life. This includes integration at school and workplaces, but extends to social life in general.

- There is a strong need to adopt a holistic approach to each individual citizen. It is important that everyone masters the daily situation. Continuity of care should be guaranteed. In particular the transition from childhood to adult age should become smoother. The latter concern, in particular, involves training and education of GPs and healthcare professionals in non-paediatric hospitals, not used to treat RD. It is necessary that this task is taken over by Centres of Expertise. However quite a number of concerns were also raised particularly around the lack of funding for social care services, especially in the current economic climate, as cutbacks are expected.
- In order to overcome the fact the RD are often "invisible" to social services, it would be beneficial for RD patients to design for them consistent, validated and evidence based healthcare pathways (see Area 4), covering a spectrum of conditions and symptoms. This would be particularly beneficial for those with a progressive or chronic condition. Coordinating information and outlining what a "good" pathway should look like could help to provide a more consistent service across the country, thus potentially decreasing the disparity of services that patients and families currently receive.
- Again, the proposals of "case managers" (see Area 4) or a "clinical liaison nurse

fostered? (this list is not exhaustive, it just includes examples from the *EUROPLAN Recommendations, see column on the left*):

  - educational support for patients, relatives and caregivers;
  - individual support at school at different schooling level, for both pupils with rare diseases and teachers, including disease-specific good practices;
  - promotional activities aimed to foster higher education for people with rare diseases;
  - supporting mechanisms to enter and stay in school and participate in work life for people with disabilities.

- In addition to support in school and work life, what support is provided to improve accessibility, in particular to public services?

- Please discuss about patient-centred measures based on individual intervention plans or "**Complex Case Managers**". During some EUROPLAN I conferences, the creation of "case managers" or other dedicated figures devoted to each individual was proposed in order to address the specific range of needs of RD patients, with specialist knowledge of the social security system. In the French National Plan they are defined as the "element that can ensure that there is a better coordination in the care pathway of PLWRD, functioning as a link between the medical and the social needs of the patient, particularly in situations most complex due to the course of care and the need for the intervention of multiple structures and professionals." (*see column on the side, EURORDIS Paper on SSS*)

specialist" was proposed also in Workshops of Area 6. The case manager would be the professional in the most suitable position to address the specific range of needs of the RD patient. S/he would also have a sound knowledge of the welfare system, so to be able to signpost appropriately." **EURORDIS Paper on Specialised Social Services – WP6 of the EUCERD Joint Action** (page 18) "**Complex Case Managers** • A number of PLWRD require special individualised social support due to the specificities of the diagnosis and its consequences. • The Complex Case Manager concept has been emerging in some countries, France being one of the examples. The section A-5-1 of the II French National Plan for RD is dedicated to "Complex Case Managers or Insertion Technicians". • Complex Case Managers are defined in the French National Plan as the element that can ensure that there is a better coordination in the care pathway of PLWRD, functioning as a link between the medical and the social needs of the patient, particularly in situations most complex due to the course of care and the need for the intervention of multiple structures and professionals. • Complex Case Managers are promoted as a solution for PWLRD that require a strong link between medical professionals, supporting health professionals (nurses, occupational therapists, dieticians, etc.), medico-social services (psychologists, social workers, carers) and different other institutions responsible for social support or benefits (social security, employment institutions, local authorities, schools). • These professionals will then work as facilitators of the coordination of the care pathways of PLWRD guaranteeing the best articulation between the several services which support the person living with a RD in the course of their life. "	
B.4. International –supranational dimension	
EUROPLAN Recommendations V. GATHERING THE EXPERTISE ON RARE DISEASES AT EUROPEAN LEVEL 17. Gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support: (a) the sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases.	• What social guidelines can be shared based on the experiences in some European countries? • How existing tools can be best disseminated, validated? How to raise awareness on the existence of such tools?

C. Background documents

C.1 Council Recommendation of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02)

(The Council of the EU) hereby recommends that Member States:
[…]
I. PLANS AND STRATEGIES IN THE FIELD OF RARE DISEASES

1. Establish and implement plans or strategies for rare diseases at the appropriate level or explore appropriate measures for rare diseases in other public health strategies, in order to aim to ensure that patients with rare diseases have access to high-quality care, including diagnostics, treatments, habilitation for those living with the disease and, if possible, effective orphan drugs, and in particular:

(a) elaborate and adopt a plan or strategy as soon as possible, preferably by the end of 2013 at the latest, aimed at guiding and structuring relevant actions in the field of rare diseases within the framework of their health and social systems;

[…]
V. GATHERING THE EXPERTISE ON RARE DISEASES AT EUROPEAN LEVEL

17. Gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support:

(a) the sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases;

http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF

C.2 Commission Communication on Rare Diseases: Europe's challenges COM(2008)679

("Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on Rare Diseases: Europe's challenges", 11/11/2008, COM(2008)679)

[…]

5.2. Access to specialised social services

Centres of expertise may also have an essential role in developing or facilitating specialised social services which will improve the quality of life of people living with a rare disease. Help Lines, Respite Care Services and Therapeutic Recreation Programmes, have been supported and need to be sustainable to pursue their goals: awareness-raising, exchange of best practices and standards, pooling resources using Health Programme and the Disability Action Plans.

http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf

C.3 EUROPLAN Recommendations

6.3. Specialised social services

90. Specialised social services are instrumental to the empowerment of people living with rare diseases 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. Online communities are vital for establishing contacts among extremely isolated patients. Therapeutic recreational programmes encourage personal development. Respite care services give family members and carers downtime opportunities.

91. Respite Care Services have been devised to assist on a temporary basis people who normally live at home, so that their carers benefit from a pause from care giving. One of the important purposes of Respite Care Services is to give family members time and temporary relief from the stress they may experience while providing extra care for a family member affected by a rare disease. Several different approaches and services exist in offering respite care: centre-based respite care (day-centre); residential based respite care and home care.

92. Therapeutic Recreation Programmes are formally or informally organised recreation activities (e.g. summer camps, ad hoc trips) which have been planned taking into account the specific needs of children or young adults with rare diseases. Activities are centred on fun, leisure and entertainment. They may include regular or ad hoc activities.

93. Examples of social services to integrate patients in their daily life and support their psychological and educational development are:

a) educational support for patients, relatives and caregivers;

b) individual support at school at different schooling level, for both pupils with rare diseases and teachers, including disease-specific good practices;

c) promotional activities aimed to foster higher education for people with rare diseases;

d) supporting mechanisms to enter and stay in school and participate in work life for people with disabilities.

EUROPLAN recommendations on Area 6: Empowerment of patients

[…]

R 6.5 Specialised social services are supported for people living with a chronically debilitating rare disease and their family carers.

R 6.6 Specialised social services are established to facilitate integration of patients at schools and workplaces.

R 6.7 A directory of centres providing specialised social services, including those offered by patients' associations, is compiled, kept updated and communicated to national, regional and patients' websites and included in the Rapsody network.

R 6.8 Interactive information and support services for patients are promoted (such as help lines, e-tools etc).

R 6.9 Information and education material is developed for specific professional groups dealing with rare diseases patients (e.g. teachers, social workers, etc.).

http://www.europlanproject.eu/_newsite_986987/_down/results/2008-2011_2.EUROPLANGuidance.pdf

C.4 Final Report of EUROPLAN I Conferences

(Area 6, page 55 and 56)

(Comment to EUROPLAN Recommendation "R 6.5 Specialised social services are supported for people living with a chronically debilitating raredisease and their family carers.")

"In a number of countries existing programmes are unevenly distributed, not appropriate because either not targeted to RD, old fashioned or hardly accessible due to the bureaucratic hurdles necessary to receive an official acknowledgement.

- Mechanisms need to be devised to recognise and integrate RD patients into existing social services (habilitation, integration into school and workplaces, recreation and respite services), while recognising their specificities and providing quality services in response to their needs. For instance, in order to address the specific evaluation of disability in RD patients, it is important modifying the disability evaluation procedures to consider other factors apart from the functional character of the disorder, such as its chronic character, degenerative processes, behavioural aspects and outbreaks.
- It is important that NPs include such provisions and envisage concrete actions to turn them into reality. For instance, improving the legal framework could be part of the solution to speed up procedures. Financial support for such services to ensure their long-term sustainability is also requested, as well as ad hoc training for staff involved in the care of RD patients.
- It is necessary that the importance of specialised services for RD patients for patients and families is recognised. It is also demanded that their support through public money becomes a priority for the whole community. Evaluation of the services provided should be carried, quality systems should be adopted as well as guidelines, staff should receive adequate professional training. Guidelines and best practices developed at the EU level within and beyond the EC-funded Rapsody project, coordinated by EURORDIS, should be used and supported further.
- Generally speaking, existing needs for specialised social services should be identified by means of a peer-to-peer discussion. Also, social studies have been mentioned as a tool to describe how to better use and save resources in this field."

(Comment to EUROPLAN Recommendation "R 6.6 Specialised social services are established to facilitate integration of patients at schools and workplaces.")

"This Recommendation hints to the need of patients living with rare conditions to integrate into social life. This includes integration at school and workplaces, but extends to social life in general.

- There is a strong need to adopt a holistic approach to each individual citizen. It is important that everyone masters the daily situation. Continuity of care should be guaranteed. In particular the transition from childhood to adult age should become smoother. The latter concern, in particular, involves training and education of GPs and healthcare professionals in non-paediatric hospitals, not used to treat RD. It is necessary that this task is taken over by Centres of Expertise. However quite a number of concerns were also raised particularly around the lack of funding for social care services, especially in the current economic climate, as cutbacks are expected.
- In order to overcome the fact the RD are often "invisible" to social services, it would be beneficial for RD patients to design for them consistent, validated and evidence based healthcare pathways (see Area 4), covering a spectrum of conditions and symptoms. This would be particularly beneficial for those with a progressive or chronic condition. Coordinating information and outlining what a "good" pathway should look like could help to provide a more consistent service across the country, thus potentially decreasing the disparity of services that patients and families currently receive.
- Again, the proposals of "case managers" (see Area 4) or a "clinical liaison nurse specialist10 was proposed also in Workshops of Area 6. The case manager would be the professional in the most suitable position to address the specific range of needs of the RD patient. S/he would also have a sound knowledge of the welfare system, so to be able to signpost appropriately. "

C.5 EURORDIS Paper: Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies

(Written in the context of the EUCERD Joint Action WP6 - November 2012 draft)

A Paper on Specialised Social Services has been developed in the framework of Work Package 6 of the EUCERD Joint Action on Rare Diseases, of which the EUROPLAN conferences are a component. Please look at the full paper for an exhaustive review of literature.

The document is available online: http://www.eurordis.org/sites/default/files/paper-social-policies-services-eja-wp6.pdf.

The extract below provides the most recent and accurate definitions of Specialised Social Services: (Section 3, pages 15-19, draft November 2012)

3. Specialised Social Services

When referring to Specialised Social Services, it is important to remember the different types of services that exist and how these can be of assistance to families and PLWRD.

The services can be listed as:

- Respite Care Services (RCS)
- Therapeutic Recreation Programmes (TRP)
- Adapted Housing (AH)
- Resource Centres (RC)
- Other habilitation services supporting PLWRD in their daily life or in their complementary therapeutic procedures, increasing PLWRD's autonomy and quality of life.

3.1. Respite Care Services

Respite care is provided, on a short term basis, for PLWRD who either live at home or attend a respite centre, so that their carers can have a short relief from care giving. Many of the PLWRD involved might otherwise require permanent placement in a facility outside their home.

One of the important purposes of respite is to give family members and carers temporary relief from the stress they experience daily while providing care for a family member living with a RD. Respite care enables the caregivers to maintain the ability to continue care giving. The benefits to carers described in the literature also fall into these two broad categories: stress reduction and self-esteem increase; and improved family functioning (MLitt and Canavan, 2007).

A second purpose of respite 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/other caregivers. Benefits to service users mentioned in the literature are socialisation, and enjoyment of experiences outside the home (MLitt and Canavan, 2007).

Respite exists all over Europe under different names and programmes. However many countries are not familiar with the concept and as a result services are not available to PLWRD in these countries.

Respite Care Services (RCS) can be offered in various ways:

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

Respite is one of the services most often requested by family caregivers, yet it is in critically short supply, inaccessible, or unaffordable regardless of the age or disability of the individual needing assistance. While the focus has been on making sure families have the option of providing care at home, little attention has been paid to the needs of the family caregivers.

Without respite, not only can families suffer economically and emotionally, caregivers themselves may face serious health and social risks as a result of stress and exhaustion associated with continuous care giving. Three fifths of family caregivers aged 19-64 surveyed recently by the Commonwealth Fund3 reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non-caregivers.

EURORDIS believes that every person living with a RD and every carer has the right to respite. The long term implications of providing respite care involve benefits for 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.

3.2. Therapeutic Recreation Programmes

Therapeutic Recreation Programmes (TRP) for PLWRD are any organised recreation activity (summer camp, ad hoc trip) which gives PLWRD the possibility to take a break from focusing on their disease and treatment to concentrating on fun and leisure.

There are three main formats that TRP may follow:

- 'Single illness' TRP: that integrate people living with a specific condition, or for siblings of patients with a particular condition;
- 'Mixed illness' TRP: that include people living with a variety of chronic conditions, or siblings/spouses of patients with different conditions;
- 'Mainstream or integrated' TRP: that involve people living with chronic conditions, siblings/spouses of patients with chronic conditions, and other attendees not affected by any illness.

TRP tend to be residential, with some services conducting one session per year, and others conducting sessions on a year round basis. TRP sessions are relatively short in duration, typically lasting between 7 and 14 days. However, TRP length can range from half a day to 3 months.

The scope of individual TRP varies in a number of respects. While camping programmes provide recreational activities, the range of recreational activities offered differs, being influenced, for example, by factors such as the TRP's geographic location, financial considerations and the age range of participants. However, common activities include arts and crafts, canoeing, adventure, camping and horse-riding.

Leisure and recreational activities will help PLWRD gain self-confidence: opening new fields of activities and new horizons in their lives. 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 and families. TRP allow PLWRD and their families to meet these needs in a safe, friendly and well-adapted environment.

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» (Kiernan, Gormley and MacLachlan, 2004).

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).

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).

Perrin (1999), in a study carried out in the Republic of Ireland, described how siblings who were involved in age-appropriate 'sibshops' where they could meet other children who have siblings with a disability were encouraged to share experiences, ask questions and learn coping strategies. The author concluded that the children involved in the groups were extremely well-adjusted; they exhibited feelings of happiness, appreciation, consideration and love for their family and brother or sister (quoted by McGarvey and Hart, 2009).

TRP can then become a tool to not only benefit patients but also their relatives, if involved in proper shops were they can meet peers and share difficulties and strategies to cope with these. More literature can be found on the need for peer support among parents and family members consulting the same study by McGarvey and Hart (2009).

3.3. Adapted Housing

Adapted housing and related services represent a particular type of service, often associated to multi-handicaps. Sometimes called "therapeutic apartments", these services allow PLWRD to develop and enjoy some level of autonomy within the comfort of their own home, alone or with some peers, under needed supervision of supportive staff, rather than being placed in an institution.

Adapted housing might also be a specific local/regional grant awarded to the patient's family in order to pay for any house adaptation work, so to keep families from moving into other facilities or in order to adjust regular buildings to certain specific needs (wheelchair, small size, hearing disabilities, autistic spectrum disorders, etc.).

3.4. Resource Centres

A new type of service has been developed in several countries: a combination of information, social and medical services, generally defined as Resource Centre for RDs. Due to its main mission, this resource represents a Specialised Social Service.

Actions performed by Resource Centres for RDs more specifically target PLWRD, often under partnership or cooperation with Centres of Reference/Expertise or themselves being a Centre of Reference/ Expertise.

Resource Centres' services include training courses, information and guidance services, provision of information about social services, documentation and research. Daily support therapies, medical and psychological consultations are often also provided by these centres.

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.

On the social level, Resource Centres provide guidance and support to PLWRD in accessing their rights and offer them social empowerment on different levels. Additionally, these centres provide training, guidance and information to different carers, including not only the PLWRD' relatives but also social services providers and adapted education teachers. By serving all these groups, the Resource Centres have an essential role in the improvement of the global social care of PLWRD.

Resource Centres can then be seen as a service specialised in handling rare complex cases. These services can also coordinate with other complex case managers located at other regional or national services, assuring proximity support to PLWRD and families.

These services can as well be considered complementary to medical services, helping to fulfil the multidisciplinary mission of Centres of Expertise, as suggested by the Communication from the Commission and by the Council Recommendation on an Action in the Field of Rare Diseases.

These services could fit into the description of the «one-stop shop style of service for rare disorders» 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", being able to provide «flexibility and person-centred approaches which fit the service around the individual's specific needs» (McGarvey and Hart, 2009).

C.6 EUCERD Core Indicators

http://www.eucerd.eu/wp-content/uploads/2013/06/EUCERD_Recommendations_Indicators_adopted.pdf

NB: Out of the 21 EUCERD core indicators, please find below selected indicators for this specific theme.

Core Indicators – Definitions and associated answers

INDICATOR	AREA OF COUNCIL REC. (2009/ C151/02)	INDICATOR DESCRIPTION	TYPE OF INDICATOR	*SHORT* ANSWER	*DETAILED* ANSWER *(multiple answers are possible, if needed)*
CONTENT INDICATORS					
SOCIAL SERVICES					
17. Existence of programmes to support in their daily life RD patients integration	6	Rare Diseases often lead to disability and a need for continuous care. Specialised Social Services are instrumental in providing patients with a full, rewarding life. Their existence and number demonstrate the political commitment of Member States to this mission. Examples of social services to integrate patients in their daily life and support their psychological and educational development are: a) educational support for patients, relatives and caregivers; b) individual support at school, for both pupils with rare diseases and teachers, including disease-specific good practices; c) activities aimed to foster higher education for people with rare diseases; d) supporting mechanisms to participate in work life for people with disabilities.	Process	YES	**YES**, people living with RD can access general programmes for persons with a disability *(Please, specify -see examples in the indicator description-: a, b, c, d, others)*
					YES, there exist specific actions to enable real access for people living with RD to general social/ disability programmes (e.g. training, guidelines for social workers, etc.) *(Please, specify - see examples in the indicator description-: a, b, c, d, others)*
					YES, there exist specific programmes for people living with RD *(Please, specify -see examples in the indicator description-: a, b, c, d, others)*
				In progress /in development	*(Please, specify -see examples in the indicator description-: a, b, c, d, others)*
				NO	

C.7 EUROPLAN Indicators

http://www.europlanproject.eu/_newsite_986989/Resources/docs/2008-2011_3.EuroplanIndicators.pdf

Area to be explored	Aims	Actions		Indicators	Type of indicator	Answers
Empowerment of Patients	Improving patients quality of life by supporting disability programmes and social services aimed at RD	Compensating disabilities caused by rare diseases	**6.11**	**Existence of official programs supporting patients and families with disabilities**	Process	• *Not existing, not clearly stated* • *Existing, clearly stated, partly implemented and enforced* • *Existing, clearly stated and substantially implemented and enforced*
			6.12	**Existence of an official directory of social resources for patients with disabilities**	Process	• *Yes* • *No* • *In preparation*
		Supporting social services aimed at rare disease patients and their families	**6.13**	**Existence of national schemes promoting access of RD patients and their families to Respite Care services**	Process	• *Yes* • *Yes, and it includes financial support to patients/families* • *No* • *In preparation*
			6.14	**Existence of public schemes supporting Therapeutic Recreational Programmes**	Process	• *Yes* • *Yes, and it includes financial support to patients/families* • *No* • *In preparation*
			6.15	**Existence of programmes to support integration of RD patients in their daily life**	Process	• *Yes* • *Yes, and it includes financial support* • *No* • *In preparation*
		Supporting rehabilitation programmes	**6.16**	**Existence of programmes to support rehabilitation of RD patients**	Process	• *Yes* • *Yes, and it includes financial support* • *No* • *In preparation*