EUCERD JOINT ACTION DELIVERABLE

Work Package	**WP6: Specialized Social Services and Integration of Rare Diseases into Social Policies and Services.**
Deliverable	**20112201_D07-00_OTH_EN_PS_pdf**
Type of document	**Report**
Title	**Report on EUCERD guiding principles for social care in RD / draft of Expert Group Recommendations in the social field**
Lead partner	**EURORDIS (European Organisation for Rare Diseases)**
Date	**September 2015**

This work arises from the EUCERD Joint Action: Working for Rare Diseases N° 2011 22 01, co-funded through the European Union's 2nd Programme of Community Action in the Field of Health.

The sole responsibility for the information provided in this document lies with the authors: the European Commission/CHAFEA is not responsible for any use that may be made of the information contained therein.

Co-funded by
the Health Programme
of the European Union

EUCERD Joint Action – Working for Rare Diseases (EJA)
EU Health Programme 2008-2013, Contract No. 2011 22 01
Start Date: 01/03/2012 - Duration: 42 months
Coordinator: Kate BUSHBY, University of Newcastle upon Tyne

Co-funded by the European Commission

EUCERD Joint Action

Deliverable 20112201_D07-00_OTH_EN_PS_pdf

Report on EUCERD's guiding principles for social care in RD / draft of EUCERD's Recommendations in the social field

Author(s):	Dorica Dan & Raquel Castro (EURORDIS)	**Approved by the:**
		☒ WP Leader
Reviewer(s):	Victoria Hedley, UNEW	☒ Project Coordinator

Keyword List:	Rare Diseases; Social Services; Social Care; Disability; Integrated Care

Abstract:

This report focuses the main deliverable of the EUCERD Joint Action's (EJA) regarding the integration of rare diseases (RDs) into social services and social policies (Work Package 6 –WP6) – the Commission Expert Group on Rare Diseases (CEGRD) recommendations to support the integration of RDs into social services and policies. The report also mentions several outcomes of EJA WP6 which represented an important support to the elaboration of the draft recommendations.

The methodology and the procedure used for the development of the recommendations are presented as well, followed by the draft recommendations. The integral text of the draft recommendations is provided in an annex to this report.

Finally, this report presents an overview of how the outcomes of EJA WP6 and the draft CEGRD recommendations relate to other EJA WPs (notably WP4, WP7, WP8), to the CEGRD and EUCERD recommendations, as well as to other stakeholders and to upcoming EU funded projects.

Document Identifier:	**20112201_D07-00_OTH_EN_PS_pdf**	**Date of Delivery to the EC Jan 2016**
Status:	Version 3, final	**Contractual: M43**
Dissemination Level:	Public	**Actual: M43**

Document history

When	Who	Comments
30/09/2015	Dorica Dan, Raquel Castro	

Table of Contents

1. Introduction

1.1 Context and Scope

This report focuses the main deliverable of the EUCERD Joint Action's (EJA) regarding the integration of rare diseases (RDs) into social services and social policies (Work Package 6 - WP6): the Commission Expert Group on Rare Diseases (CEGRD) recommendations to support the integration of RDs into social services and policies. The report also mentions several of outcomes of EJA WP6 which represented an important support the elaboration of the draft recommendations.

These draft recommendations mainly focus on the key role of health services in facilitating integrated care provision and in supporting the integration of RDs' specifies into mainstream social services, within a holistic and patient-centred approach.

Social support in other environments, such as education, employment and leisure is not addressed in these recommendations. More comprehensive information will be gathered in an additional paper focusing on "Social Care and Inclusion for People Living with a Rare Disease", to be made available at the EUCERD website (Joint-Action section) and at EURORDIS website.

1.1.1 Key principles behind the EUCERD Joint Action work on the integration of RDs into social services and policies

- Health is a state of complete physical, mental and social well-being (World Health Organisation, 1946);
- Social services contribute to core values and objectives of the EU Member States and of the EC, such as achieving a high level of employment, social protection, health protection, gender equality, and economic, social and territorial cohesion (Huber M. et al., 2006);
- Social services aim at improving citizens' quality of life and at providing social protection. They assist vulnerable individuals and persons who have a range of special needs and risks, such as those needing long term care or facing disability, poverty and being at risk of social exclusion (Huber M. et al., 2006);
- Social care consists of helping people live their lives comfortably, particularly those who require extra help. Social care workers help individuals maintain their independence, which increases their quality of life and to helps them lead fuller more enjoyable lives (National Institute for Social Work, UK);
- Social services are often closely interlinked with health services. Experts consider that there is a need for a chain of actors and providers to take care of individual needs and to provide solutions in an integrated and coordinated manner (Huber M. et al., 2006);
- Supporting integrated care and the integration of RDs' specificities into mainstream social and local services is efficient and essential to improve the quality of life of people living with a RD;
- People living with a RD are entitled to standards of care that recognise the challenges of rare complex conditions and equivalent to the ones provided to citizens with similar requirements;
- Patients and families affected by RDs are entitled to participate in decisions regarding their care plan and their life project. Care providers should support and empower them to express their wishes, set their priorities and take decisions.

1.2 Background

1.2.1 About rare diseases

Rare diseases (RDs) affect a small number of people compared to the general population. A disease is defined as rare in Europe when it affects less than 1 in 2000 people. Although each RD is characterised by a low prevalence, RDs affect 30 million people in the Europe. Most patients suffer from less frequent diseases affecting 1 in 100 000 people or less and are consequently particularly isolated and vulnerable.

Rare diseases are very heterogeneous in terms of prevalence, age of onset, clinical severity and outcome. Nonetheless, they share various common features: they are serious, often chronic, progressive, degenerative and associated with comorbidities. RDs may affect patients in different ways (i.e. nervous system, eyesight, skin, size, cognition, behaviour, etc.) and are often multisystem disorders, affecting various organs and tissues.

Rare diseases are at the origin of various severe impairments and a high percentage of people with a RD is affected by motor or intellectual impairments, which can occur simultaneously[1] (Guillem et al, 2008; Tozz et al, 2013). RDs substantially affect life expectancy and altogether account for a considerable rate of the early-life deaths and life-long disabilities in the European population (Rare Diseases Task Force, 2008).

1.2.2 Unmet medical and social needs of people with a rare disease

The unmet social needs of people with a RD and their families affect their dignity, autonomy and other fundamental human rights expressed in the Universal Declaration of Human Rights and in the United Nations Convention on the Rights of Persons with Disabilities.

The cumulative effects of illness and disability generated by RDs amplify the effects of social exclusion experienced by patients and their relatives. People living with a RD face significant challenges accessing school, employment, leisure, transport, adapted housing, bank credit, to name a few. Patients and families are therefore psychologically, socially, economically and culturally vulnerable.

The social challenges faced by RD patients and families include, for instance, the necessity to reduce or stop professional activity for the patient or one member of the family, the need to relocate to another home adapted to their health needs, and difficulties in meeting with a social worker (EURORDIS, 2009)[2]. Additional challenges comprise needs of support in domestic life, transport and mobility, leisure activities, educational or professional activities and self-care, financial burden and feelings of discrimination in the labour market (FEDER, 2009[3]; McGarvey and Hart, 2008).

Family members – often the main carers – frequently find themselves in burn out situations, unable to cope physically and psychologically with the situation.

The particular context of RDs generates an important moral suffering (French Social and Economic Council, 2001) and it has been recognised that these diseases result in reduced quality of life and affect individuals' potential for education and earning abilities (Schieppati et al, 2008). Compared to more prevalent chronic disorders, people living with a RD have a worse quality of life and experience more difficulties in terms of loss of social and economic activities, not to mention medical care (Van Nispen, 2003).

A Comprehensive literature review and overview of rare disease patients' unmet social needs was compiled by EJA WP6 in the document "Rare diseases: addressing the need for specialised social services and integration into social policies" available on the website of the EUCERD Joint Action and on EURORDIS website.

1.2.3 Challenges for the Integration of RDs into Social Services and Social Policies

Providing holistic care to people living with Rare Diseases (RDs) is particularly challenging because:

- Expertise and knowledge on RDs and their consequences are scarce and difficult to access leading to lack knowledge on rare conditions among professionals (Kemper et al, 2006; Berglund et al, 2010);
- Care provision patients and families affected by a RD needs to be multidisciplinary, including medical and paramedical care as well as social, psychological or educational aspects (EUROPLAN, 2011). Patients and families need to be followed simultaneously by a set of national, regional and local health, social and complementary services which are often managed by different authorities;
- Patients and families affected by RDs often need continuous and lifelong support, and transition periods can be particularly challenging (i.e. from childhood to adulthood).

[1] Guillem et al, 2008 - France, 1739 children with RDs: a RD was at the origin of 26% of cases of severe neuromuscular impairment; proportion of impairments due to a RD: 3.3% for severe psychiatric disorders; 16.0% for intellectual impairment; 37.2% for hearing impairment; 41.2% for neuromuscular, skeletal, movement impairment; 81.1% for visual impairment; Tozzi et al, 2013 - Italy, 516 parents of children with a RD: nearly 70% of patients born to respondents had a disability (49.2% motor; 33.3% intellectual; 22.4% both).

[2] Survey involving 12000 patients from 23 countries (2002-2008) - 1/3 of the respondents reported that a patient in their family had to reduce or stop professional activities due to the disease; an additional 1/3 of the respondents reported that one member in the family had to reduce or stop professional activities to take care of a relative with a RD; almost 1/3 of the respondents required assistance from a social worker in the 12 months preceding the survey. More than 1/3 of those reported they met the social work with difficulties or did not meet one at all; 1/5 of the respondents had to move house, usually to relocate to a home better adapted to their health needs.

[3] Study performed in Spain (2009) - patients mentioned that they generally need support for: domestic life (46%), transport (42%), personal mobility (40%), leisure activities (37%), educational/professional activities (39%), self-care (32%). Only 1 in 10 did not need any sort of assistance in daily life; 27% spend income in adapted transport, 23% in personal assistance and 9% in adapting their house;, patients reported to feel discriminated in: leisure activities (32%), education (30%) and daily activities (29%); labour market (32%) either when searching for a job (17%) or at their current job (15%).

Adding to these challenges people with RDs experience barriers in access to health and welfare services (Grut and Kvam, 2013):

- Care systems are usually designed around common diseases and mainstream services are not flexible enough to take into consideration unprecedented health needs (EURORDIS, 2009; Kodra, et al, 2007[4]; Hennepe, 1999 quoted by McGarvey and Hart, 2008[5]);
- The care system consequently becomes extremely difficult to navigate for patients and their families who struggle to make the most of their potential throughout their life course; accessing appropriate social care services is a lengthy and complex process (Griffith, et al, 2011);
- The care pathway is currently fragmented and several steps are very difficult and problematic, such as obtaining the correct diagnosis, the needed social care and aids, managing the transition between hospital and home, as well as the transition between child and adult care (Brains for Brain Foundation, 2014); patients feel that they have to constantly chase up services and experienced frustration at the fragmentation of services (McGarvey and Hart, 2008);
- There is a lack communication and coordination within and between the health and social care sectors, as well as between national and local services (Byskov Holm, 2015);
- Professionals are insufficiently informed and trained to care for people living with a RD and tend to be reluctant to treat patients and families due to the complexity of their disease (EURORDIS, 2009);
- In most cases, the management and coordination of care have to be done by the patient or the patient's family, putting heavy burdens on family life (Dammann, 2015).

These bottlenecks are of particular importance when considering that the perception that RD patients and families have on their quality of life of is more closely linked to the quality of care provided than to the gravity of the illness, or the degree of the associated disabilities (EURORDIS, 2009).

The deliverable produced within EJA WP6 – the draft CEGRD recommendations to support the integration of RDs into social policies and services – builds up on the context of RDs and the challenges of caring for RD patients and families to elaborate recommendations that support the EU and MS to improve the integration of RD specificities into mainstream services and policies.

[4] In the framework of the Network of Public Health Institutions on Rare Diseases, a European project, funded by the European Commission, 302 questionnaires were completed by patients and caregivers in France, Italy, Romania, Spain, Turkey and United Kingdom during 2004-05. «In general, respondents thought that health care accessibility was worse than quality and that social care and legal provisions were worse than health care (Kodra, et al., 2007).

[5] Hennepe's research focused on care in RDs concluded that a multi-disciplinary approach is needed for RD patients/families. Additionally, many family members who participated in this research felt that people with RDs are often unsuitably placed within generic services. Some participants felt that there was an expectation for them to fit into generic services and that this often did more harm than good in terms of their progress. The majority of the family participants in this research felt that there was a huge need for all services to respond to the unique and complex needs of RD patients.

2. Presentation of results - CERGD draft recommendations

2.1 Methodology

Various initiatives of EJA WP6 have contributed to the CEGRD recommendations to support the integration of RDs into social services and policies:

- Background document: EUCERD Joint Action: Rare Diseases – Addressing the Need for Specialised Social Services & Integration into Social Policies (November 2012);
- Mapping, fact sheets and case studies of specialised social services for RDs (2012-2015);
- Workshop on Specialised Social Services for RDs, 6-7 December 2012, Zalau, Romania - EUCERD Joint Action Guiding Principles for Specialised Social Services (April 2013);
- Workshop on training of social service providers, 10-11 October 2013, Copenhagen - EUCERD Joint Action Guiding Principles on Training for Social Services Providers (April 2014); EUCERD Joint Action Examples of Training Programmes for Social Service Providers.

The draft recommendations were also based on the outputs of several key European publications:

- Communication from the Commission on Rare Diseases: Europe's Challenges (2008);
- Council Recommendation on an Action in the Field of Rare Diseases (2009);
- EURORDISCare Survey – The Voice of 12000 patients (EURORDIS, 2009);
- EUROPLAN Report on the 15 National Conferences (2010-2011);
- EUROPLAN National Conferences reports (2012-2015) and National Plans/Strategies for RDs.

The draft recommendations underwent a consultation process involving members of the CEGRD, partners of the EUCERD Joint Action, EUROPLAN advisors, members of the EURORDIS Social Policy Advisory Group and other relevant stakeholders in the field of health and social care.

2.2 Recommendations

The draft recommendations are presented below, divided into four main groups: policy recommendations; recommendations to facilitate integrated patient-centred care for people with a RD; recommendations to support the integration of RD specificities into mainstream services; and recommendations on research.

Policy Recommendations

1. **Centres of Expertise to undertake a key role in facilitating integrated care provision in line with the EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases (4, 5, 8, 9, 10) and the recommendations of the EUCERD Joint Action report on 'Centres of Expertise and Quality of Care for Rare Diseases' (11):**
   - Centres of Expertise (CEs) bring together, or coordinate, within the specialised healthcare sector multidisciplinary competences/skills, including paramedical skills and social services;
   - CEs contribute to building healthcare pathways from primary care;
   - CEs contribute to the elaboration of good practice guidelines and to their dissemination;
   - CEs provide education and training to (…) non-healthcare professionals (such as school teachers, personal/homecare facilitators);
   - CEs contribute to and provide accessible information adapted to the specific needs of patients and their families, of health and social professionals;
   - CEs should include, or include access to, a level of support staffing (e.g. social worker) sufficient to cover liaison and linked activities involving social care providers, social services, patient organisations and other external stakeholders.
2. **European Reference Networks for RDs to undertake a key role in facilitating integrated care provision in line with the EUCERD recommendations on European Reference Networks for Rare Diseases (10) and the Directive on patients' rights in cross-border healthcare (12):**
   - Rare Disease European Reference Networks (RD ERNS) need to collaborate with health and social care providers;

- RD ERNs facilitate mobility of expertise, virtually or physically, and develop, share and spread information, knowledge and best practice;
- RD ERNs follow a multi-disciplinary approach; organise teaching and training activities; and collaborate closely with other CEs and networks at national and international level.

3. **The integration of RDs' specificities into social services and policies is a key issue for the elaboration or revision of National Plans and national strategies for RDs**

- Measures promoting integrated holistic care for people living with a RD should be included in national policies for RDs currently under development or up for revision;
- National policies should encourage cooperation between public, private and civil society (e.g. patient organisations) in order to promote the integration of the social dimensions of care and RDs' specificities into mainstream services;
- European policies can provide a framework with key elements to be agreed among stakeholders.

4. MS should allocate funding to key activities which facilitate the sharing of expertise and the improvement of holistic care provision for people living with a RD, namely:

- Activities which support the multidisciplinary work between CEs, social services, local services and patient organisations (e.g. coordination, networking, sharing of information and good practices, training);
- Training courses for persons affected by RDs, including family members, as well as financial support for attendance of training courses (e.g. support for transport costs).

Recommendations to Facilitate Integrated Patient-Centred Care for People with a RD

5. **MS promote measures that facilitate integrated and continuous patient-centred and participative care provision to people living with rare diseases**

- Care pathways and standards of care for RDs should be developed and used as tools to level care and services provided to people living with RDs;
- Individual care plans, based on the assessment of individual needs, including health and social dimensions of care, should be developed and implemented in coordination between care providers, together with RD patients and their family;
- Case managers, responsible for coordinating the development and follow up of the individual care plans – including the establishment of networks of care providers, provision of information and support to patients and families, oversee of appointment of care workers, etc. – should be employed by or work in close connection with CEs. Case managers should be training by CEs, in line with the EUCERD Recommendations on Quality Criteria for Centres of Expertise on Rare Diseases (9). Furthermore, MS should consider to describe the role and responsibility of case managers as part of standards of care for RDs;
- CEs should work closely with 1) existing one-stop-shop support services for RDs, such as Resource Centres for RDs; 2) existing specialised social services for RDs (therapeutic recreation programmes, respite care services, adapted housing programmes) as these services are key facilitators for the provision of holistic care;
- Individuals, as patients or as people with disabilities, should be involved in the care process.

6. **RDs specificities should be integrated into national incapacity assessment systems in line with the United Nations Convention on the Rights of Persons with Disabilities**

- The functioning and disability assessment system should to take into account that the complex combination of several impairments linked to a RD may lead to a more severe disabilities and have a much higher impact on a the person's life than one or a sum of particular impairments;
- The assessment system should be flexible to adapt to people with a RD affected by less visible impairments, degenerative conditions or acute disease periods;
- The exchange of information and the communication between CEs and assessment bodies should be encouraged to allow for better assessment of the needed compensation measures;
- Additional tools to integrate RD specificities into the assessment process should be developed based on the International Classification of Functioning, Disability and Health (ICF). MS should develop these tools collectively to avoid loss of knowledge transferability between experts in different countries;

- The Orphanet Disability Project which develops RD disability core sets derived from and compatible with the ICF is an important tool that can support MS accessing the information necessary to improve the assessment of functionality and disability of people living with a RD.

Recommendations to Support the Integration of RDs' specificities into mainstream services

7. **Training of professionals to be promoted as essential to support the integration of RD specifies into mainstream services**
   - Training social services providers is an essential and efficient means of increasing awareness for RDs, empowering social care professionals, optimising the use of resources, creating synergies for progress and increasing the quality of care;
   - Training programmes for social services providers should be promoted with the objective of making professionals aware of RDs and their specificities, of where they can find information and of how they can improve the quality of the services provided to people with a RD;
   - CEs should take the lead in developing training and networking programmes/tools for social and local support services professionals involved in the different stages of the care pathway;
   - Training courses should be promoted within a cooperative multidisciplinary approach involving CEs, patients/families and the other relevant stakeholders;
   - The EUCERD Joint Action documents on Guiding Principles for Training of Social Services Providers and on examples of training programmes should be used to support the design of training programmes for social care providers.
8. **Training to patients and families affected by a RD should be supported in order to empower them and to promote their autonomy and their capacity to undertake a participative role in care provision**
   - MS should support the development of training programmes for people living with a RD and their families in coordination with care providers and patient organisations in order to empower patients and their families to exercise their rights and to increase their self-esteem, their autonomy and their quality of life.
9. **The elaboration and dissemination of good practices for social care in RDs should be encouraged**
   - The EUCERD Joint Action Guiding Principles for Specialised social services and case study documents should serve as inspiration to MS and to care providers;
   - Generic protocols should be developed at national or EU level, in coordination between care providers and patient organisations, defining broad guidelines and methodologies for social care, service and support in the RD field. These common tools should be flexible to adapt to different countries and across patients with distinct individual needs;
   - Existing Resource Centres for RDs, for specific diseases or disabilities should be used as a platform to collect and disseminate best practices for social care, service and support.
10. **Information and data sharing should be promoted in order to facilitate access to the rights of people with disabilities resulting from a rare disease, including holistic care provision**
    - Interoperability and transfer of information between care providers, within the limits of data protection legal frameworks, is key to the success of holistic care provision to RD patients;
    - Information on RDs and links to reference national and international websites (e.g. Orphanet) should be available and easily accessible on a national portal;
    - MS should consider developing a complete and up-to-date national RD information hub (e.g. via Orphanet or via Resource centres for RDs when existing) to serves as a one-stop-shop portal for information on CEs, research, therapies and social services available in the country;
    - Orphanet's disability fact sheets and guidelines developed at national level should be disseminated in MS to social care providers at national, regional and local levels.
    - Existing help lines for RDs should be promoted as support services that collect and provide information and knowledge on RDs as well as direct support to patients and families.

11. MS should promote coordination and networking between all parties involved in care provision of persons affected by RDs as well as between providers and patient organisations

- MS should facilitate the development of a system to bring together all parties involved in the provision of holistic care to people living with RD, including the users themselves;
- A national multi-sectorial working group on RDs should be a created in each MS, subject to centralised monitoring at regular intervals;
- MS should promote the creation of multidisciplinary teams composed by health, social and local care professionals to ensure transfer of knowledge/expertise from central structures to regional/local services and support the provision of holistic and continuous care;
- Funding should be allocated to networking activities between care providers, notably between CEs and care providers at local level, be it e.g. through funding attributed to CEs for this effect or through funding of local authorities provided to local services to this purpose.
- Networking at international level should be facilitated via RD ERNs and by having national Resource centres for RDs included in the contact network of ERNs when relevant.

Recommendations on Research

12. Social research and surveys should be promoted in order to collect data on unmet social and psychological needs, on the socio-economic impact of social care provision

- MS should support the creation of research programmes to collect data on the dimension of the need for social care in RDs in order to support decision making in regards to care provision;
- Further investment should be made on promoting socio-economic research programmes on:
    - Social and daily life unmet needs from people living with a RD and their families;
    - Efficacy and cost-effectiveness of social services and support to people with a RD as opposed to costs generated by the absence of provision of holistic care;
    - Environmental barriers affecting people with a RD;
    - Comparative analysis between disability and social issues in people with and without a RD.
- Top priority should be given to funding and implementing solutions to maximise the input of information and minimise the use of resources in collecting data e.g. use of registries, CEs or case managers to collect key information and self-reporting systems for patients and families.

3. Conclusion

The draft recommendations were elaborated taking into account other important EU documents and on previous EUCERD recommendations such as the EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases and the EUCERD recommendations on European Reference Networks for Rare Diseases. Additionally, all the work of EJA WP6 leading to these recommendations, has been conducted in close collaboration with EJA partners and WPs, notably with WP4 – National Plans, WP7 – Health Care Systems and WP8 – Integration of Rare Diseases into Thematic Areas.

EJA WP6 contributed the development of the content guidelines for EUROPLAN national conferences. Additionally, the reports from the national conferences as well as the adopted National Plans/Strategies for RDs were used to collect good practices in MS. These became an essential element for the preparation of the draft recommendations. EJA WP6 was also in constant interaction with EUROPLAN advisors to get their input for the various workshops and documents prepared.

EJA WP6 worked in close collaboration with WP7, following up on the case studies and findings of the visits to Centres of Expertise in MS and providing input to the EUCERD Joint Action report on 'Centres of Expertise and Quality of Care for Rare Diseases'. The knowledge shared by WP7 and the outcome recommendations included in the report were an asset to the elaboration of these draft recommendations.

The University of Newcastle (UNEW), as coordinator and leader of WP8 as well as other EJA partners, EUROPLAN advisors and EUCERD/CEGRD representatives have been involved in the workshops organised and in the documents produced.

In order to enrich the quality of the reflections and of the documents elaborated, EJA WP6 reached out to other partners in the social field (i.e. specialised social services, the International Federation of Social Workers). Creating these partnerships was essential to guarantee the input of the social sector into the various documents and these draft recommendations.

The follow up on these draft recommendations, comprising new discussions at the CEGRD meetings and new consultations to all stakeholders, will be performed within the RD-Action ('677024/RD-ACTION' which has received funding from the European Union's Health Programme, 2014-2020).

EJA WP6's mapping, partnerships, guiding principles and recommendations also supported the development of a new EU funded project (DG Employment, VS/2015/0209), entitled INNOVCare – Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions.

INNOV-Care will address the issue of integrated care for people affected by RDs by developing, testing and promoting a holistic, personalised social pathway involving public, private and civil society organisations.

The innovative horizontal approach brings together national one-stop-shop services for RDs (resource centres defined and mapped during EJA WP6) and regional case managers, in partnership with public bodies. In addition, the project establishes a European Network of Resource Centres and Case to collect good practices vital to improve quality of care, in line with the Voluntary EU Quality Framework for Social Services.

The care pathway of INNOVCare proposes that: on one hand the case handlers at regional level rely on the national resource centre to gather expertise by concentrating patients with the same RDs and good practices; on the other hand, national centres rely on the expertise of centres in other countries and on the patient outreach capacity of the regional case handlers.

The new care model will be implemented and evaluated in a pilot in Romania. INNOV-Care will also conduct robust data collection on the cost-benefit of the proposed care model. EURORDIS is responsible for 3 WPs on INNOVCare: Communication; State of the Art of Social Care Provision in MS including survey on patients' unmet social needs; European Network of Resource Centres and Case Managers for Rare Diseases.

The new partnerships to be developed within INNOVCare will be key to support the ongoing efforts from the EU and MS to integrate of rare diseases into social services and social policies, and to promote integrated holistic care provision to patients and families affected by rare diseases side by side with the CEGRD recommendations.

4. References

EU Documents

Communication from the Commission on Rare Diseases: Europe's Challenge: http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf .

Council Recommendation of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02): http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2009:151:0007:0010:EN:PDF.

Communication from the Commission on European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF.

Directive on patients' rights in cross-border healthcare, 9 March 2011(2011/24/EU): http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:EN:PDF.

EUCERD recommendations

EUCERD recommendations on Quality Criteria for Centres of Expertise on Rare Diseases in Member States (2011): http://www.eucerd.eu/?post_type=document&p=1224.

EUCERD recommendations on European Reference Networks for Rare Diseases (2013): http://www.eucerd.eu/?post_type=document&p=2207.

EUCERD Joint Action Documents

Paper "Rare Diseases: Addressing the Need for Specialised social services and Integration into Social Policies", written in the context of EUCERD Joint Action, Work Package 6, November 2012: http://www.eurordis.org/sites/default/files/paper-social-policies-services-eja-wp6.pdf.

Workshop Report: 'Guiding Principles for Social Care in Rare Diseases' (Norway, 2014): http://www.eurordis.org/sites/default/files/eja-wp6-workshop-report-guiding-principles-social-care.pdf.

Workshop Report: 'Guiding Principles for Specialised social services' (Denmark, 2013): http://www.eurordis.org/sites/default/files/EJA-WP6-Workshop-Report-Guiding-Principles.pdf.

Workshop Report: 'Training for Social Services Providers' (Romania, 2012): http://www.eurordis.org/sites/default/files/eja-wp6-workshop-report-training-social-services-providers.pdf.

Document 'Guiding Principles for Specialised social services': http://www.eurordis.org/sites/default/files/EJA-WP6-Guiding-Principles-Specialised-Social-Services.pdf.

Document 'Guiding Principles on Training for Social Services Providers': http://www.eurordis.org/sites/default/files/training-for-social-services-providers.pdf.

Map and information on Specialised social services: http://www.eurordis.org/specialised-social-services.

Centres of Expertise and Quality of Care for Rare Diseases. Report from the EUCERD Joint Action WP7 (DG SANCO 20112201, EU Health Programme). January 2015. http://www.eucerd.eu/wp-content/uploads//2015/03/WP7_SummaryReport_CentresExpertiseRD_2015.pdf.

Case Studies and Fact sheets on Social Services

Therapeutic Recreation Programmes: http://www.eurordis.org/content/therapeutic-recreation-fact-sheet-case-studies.

Respite Care Services: http://www.eurordis.org/content/respite-care-fact-sheet-case-studies.

Adapted Housing Services: http://www.eurordis.org/content/adapted-housing-fact-sheet-case-studies.

Resource Centres for RDs: http://www.eurordis.org/content/resource-centres-fact-sheet-case-studies.

National Plans and National Conferences

EUROPLAN final report recommendations based on the 15 EUROPLAN National Conferences (2010-2011): http://download.eurordis.org.s3.amazonaws.com/rdpolicy/final-report-europlan-15-national-conferences.pdf.

National Plans for Rare Diseases: http://www.europlanproject.eu/NationalPlans?idMap=1.

Reports from EUROPLAN National Conferences (2012-2015): http://www.eurordis.org/content/reports-europlan-national-conferences-2012-2015.

Presentation 'How National Plans can address Social Issues', Simona Bellagambi, ECRD 2014 Berlin: http://www.rare-diseases.eu/wp-content/uploads/2014/05/0601_Simona_Bellagambi.pdf.

Presentation 'How National Plans can address Social Issues. Case study: the experience of France', Christel Nourissier, ECRD 2014 Berlin: http://www.rare-diseases.eu/wp-content/uploads/2014/05/0601_Christel_NOURISSIER.pdf.

Other References

A. Schieppati, J. I. Henter, E. Daina, and A. Aperia, "Why rare diseases are an important medical and social issue," Lancet, vol. 371, no. 9629, pp. 2039–41, 2008

Berglund B, Mattiasson AC, Randers I. Dignity not fully upheld when seeking health care: Experiences expressed by individuals suffering from Ehlers-Danlos syndrome. Disability and Rehabilitation. 2010;32(1): 1-7

Brains for Brain Foundation, Dr Horst Schmidt Klinik. Healthcare Transition of Adolescent Rare Disease Patients. Position Paper. 2014. http://www.innermed.eu/uploads/assets/6_BfB_Transition_Paper_Final_03022015.pdf.

Byskov Holm B, Jensen L. Only the strong survive - Said by a mother navigating the welfare systems. Rare Diseases Denmark. 2014. http://www.rare-diseases.eu/wp-content/uploads/2013/08/12_t1.pdf. Accessed 18 Sept 2015.

Dammann B. Does an individual plan make better services for children with rare disorders? Int J Integr Care. 2015. Annual Conf Suppl. URN:NBN:NL:UI:10-1-117075. http://www.ijic.org/index.php/ijic/article/view/2067/2864 (2015).

De Vrueh R, PhD, Baekelandt ERF, de Haan JMH. Background paper 6.19, Rare Diseases, Update on 2004 Background paper by Van Weely S, Leufkens HGM. In: Warren Kaplan et al. Priority medicines for Europe and the world: "A public health approach to innovation", Update Report. World Health Organization. 2013.

EURORDIS. The Voice of 12 000 Patients. Experiences and expectations of rare disease patients on diagnosis and care in Europe. Paris: EURORDIS; 2009 http://www.eurordis.org/IMG/pdf/voice_12000_patients/EURORDISCARE_FULLBOOKr.pdf.

Federación Española de Enfermedades Raras. Study on the Situation of Social-sanitary Needs of People with Rare Diseases in Spain – ENSERio. 2009.

French Social and Economic Council: « Cinq mille maladies rares, le choc de la génétique : constat, perspectives et possibilités d'évolution », Journal officiel de la République française, Avis et rapports du Conseil économique et social, 2001, Rapporteur : Bernard Barataud (p.6), http://www.lecese.fr/sites/default/files/pdf/Avis/2001/01092516.pdf.

Grut L, Kvam MH. Facing ignorance: people with rare disorders and their experiences with public health and welfare services. Scandinavian Journal of Disability Research. 2013; 15(1). doi:10.1080/15017419.2011.645870

Grut L, Kvam MH: Facing ignorance: people with rare disorders and their experiences with public health and welfare services; Scandinavian Journal of Disability Research 15:1, 20-32, 2013

Hennepe, L., 1999. Rare diseases need structured care: the diagnosis is just the start. *Tijdschrift voor Huisartsgeneeskunde*, 16 (7/8): 374–376.

http://www.who.int/medicines/areas/priority_medicines/BP6_19Rare.pdf.

Huber M., Maucher M., Sak B. 'Study on Social and Health Services of General Interest in the European Union - prepared for DG Employment, Social Affairs and Equal Opportunities', 2006.

INNOVCare: Project funded by the European Commission, DG Employment, Social Affairs and Inclusion, under Grant agreement VS/2015/0249. http://www.innovcare.eu/ (2015).

International Classification of Functioning, Disability and Health: http://www.who.int/classifications/icf/en/

Kemper AR, Uren RL, Moseley KL, Clark SJ. Primary care physicians'attitudes regarding follow-up care for children with positive newborn screening results. Pediatrics. 2006;118(5): 1836-41.

Kodra, Y. *et al*., 2007. Access to and quality of health and social care for rare diseases: patients' and caregivers' experiences. *Annali di igiene : medicina preventiva e di comunità*, Mar-Apr;19(2):153-60.

Le GEVA, Évaluer les besoins de compensation. LES CAHIERS PÉDAGOGIQUES DE LA CNSA, SEPTEMBRE 2012: http://www.cnsa.fr/IMG/pdf/CAHIERpedagogique_GEVA_Web.pdf.

McGarvey B, Har C. An investigation into the social support needs of families who experience rare disorders on the island of Ireland. RehabCare. 2008. http://www.rehab.ie/about/PDFS/July2008/RehabCare_RD_Report.pdf.

Möller, K. (2008) Impact on participation and service for persons with deaf-blindness. Linköping & Örebro Universities, Swedish Institute for Disability Research.

National Institute for Social Work, United Kingdom: http://www.nisw.org.uk/socialcare/.

Nispen RMA van, Rijken PM, Heijmans MJWM. Leven met een zeldzame chronische aandoening: Ervaringen van patiënten in de zorg en het dagelijks leven. Nivel, 2003. ISBN 90-69056-14-3. 148 pages quoted in A. Schieppati, J. I. Henter, E. Daina, and A. Aperia, "Why rare diseases are an important medical and social issue," Lancet, vol. 371, no. 9629, pp. 2039–41, 2008

Orphanet, "About Rare Diseases". Pu

Orphanet Disability Fact Sheets, Syndrome de Williams: https://www.orpha.net/data/patho/Han/fr/Handicap_Williams-FrfrPub145v01.pdf.

Orphanet. List of rare diseases and synonyms listed in alphabetical order. Orphanet Report Series, Rare Diseases collection. May 2015. http://www.orpha.net/orphacom/cahiers/docs/GB/List_of_rare_diseases_in_alphabetical_order.pdf.

Orphanet, "About rare diseases", 2012. http://www.orpha.net/consor/cgi-bin/Education_AboutRareDiseases.php?lng=EN.

Orphanet "What is an orphan drug?". http://www.orpha.net/consor/cgi-bin/Education_AboutOrphanDrugs.php?lng=EN.

Orphanet: an online database of rare diseases and orphan drugs. Copyright, INSERM 1997. Available at http://www.orpha.net.

P Guillem, C Cans, E Robert-Gnansia, S Aymé, P S Jouk. Rare diseases in disabled children: an epidemiological survey. Arch Dis Child 2008;93:2 115-118 Published Online First: 17 October 2007 doi:10.1136/adc.2006.104455

Rare Diseases Task Force. Health indicators for Rare diseases: State of the art and Future directions. 2008. http://www.eucerd.eu/?post_type=document&p=1207.

Schieppati A, Henter JI, Daina E, Aperia A. Why rare diseases are an important medical and social issue. Lancet. 2008;371:2039–2041. doi: http://dx.doi.org/10.1016/S0140-6736(08)60872-7.

'Study on Social and Health Services of General Interest in the European Union - prepared for DG Employment, Social Affairs and Equal Opportunities'. Huber M., Maucher M., Sak B. (2006)

Syed AM, Camp R, Mischorr-Boch C, Houÿez F, Aro AR. Policy recommendations for rare disease centres of expertise. Eval Program Plann. 2015 Oct; 52:78-84.

The internet user profile of Italian families of patients with rare diseases: a web survey. Tozzi AE, Mingarelli R, Agricola E, Gonfiantini M, Pandolfi E, Carloni E, Gesualdo F, Dallapiccola B.Orphanet J Rare Dis. 2013 May 16;8:76. doi: 10.1186/1750-1172-8-76. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3662591/.

Tozzi, Rita Mingarelli, Eleonora Agricola, Michaela Gonfiantini, Elisabetta Pandolfi, Emanuela Carloni, Francesco Gesualdo and Bruno Dallapiccola. Orphanet Journal of Rare Diseases 2013, 8:76

United Nations Convention on the Rights of Persons with Disabilities: http://www.un.org/disabilities/convention/conventionfull.shtml.

Universal Declaration of Human Rights: http://www.un.org/en/documents/udhr/.

Voluntary European Quality Framework for Social Services: http://bit.ly/1OX4nG9.