EUCERD JOINT ACTION GUIDING PRINCIPLES

ON TRAINING FOR SOCIAL SERVICES PROVIDERS

TO THE EUROPEAN COMMISSION, MEMBER STATES AND ALL STAKEHOLDERS

April 2014

INTRODUCTION

The specificities of rare diseases (RDs) – low prevalence, great heterogeneity of diseases and symptoms, scarcity of treatment and of knowledge/expertise – single them out as a domain for which professionals' training is vital.

The following guiding principles have been based on the outputs of the multi-stakeholder workshop on 'Training for Social Services Providers' (Copenhagen, October 2013), of the EUCERD Joint Action Work Package 6 'Specialised Social Services and Integration of Rare Diseases into Social Policies and Services', as well as on the consultation of several expert advisors amongst patients, scientific community and policy makers, and previous publications, including:

- The Communication from the Commission on Rare Diseases: Europe's Challenges (2008)[1];
- The Council Recommendation on an Action in the Field of Rare Diseases (2009)[2];
- The EUROPLAN Report on the 15 National Conferences (2010-2011)[3];
- The policy background and literature review EUCERD Joint-Action document 'Rare Diseases: Addressing the Need for Specialised Social Services and Social Policies[4];
- As well as other important European surveys and studies.

These principles will be distributed at the meeting of the Commission Expert Group on Rare Diseases in July 2014.

1. BACKGROUND TO THE GUIDING PRINCIPLES

A disease is defined as rare in the European Union (EU) when it affects no more than 5 in 10.000 people. There are between 5.000 and 8.000 distinct rare diseases. Although each RD is characterised by low prevalence, it is estimated that 30 million people in the EU are or will at some point be affected by a RD.

Rarity generates additional difficulties for patient care. Due to the low prevalence of each disease, scientific knowledge and expertise are scarce and difficult to access. Professionals often have difficulties in gathering information about the diagnosis, their spectrums and even the variations of symptoms between patients with the same disease. There is little knowledge on the daily life consequences for patients and families.

Complexity is another feature of RDs, which often require follow up by interdisciplinary teams that need to be prepared to face the uncommon and very specific challenges generated by these diseases.

Scarcity of treatment comes hand in hand with RDs. After a usually long waiting time before reaching the right diagnosis, most patients and families come to discover that there is neither treatment, nor cure. Rare diseases are thus often chronic and demand from patients, families and professionals a lifelong adaptation to living and coping with a RD.

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[1] 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 November 2008, COM(2008) 679.
[2] Council Recommendation of 8 June 2009 on an action in the field of Rare Diseases (2009/C 151/02)
[3] Document may be downloaded from the EUROPLAN website (http://www.europlanproject.eu/)
[4] Document may be downloaded from the EUCERD website (http://www.eucerd.eu/)

Rare diseases are hence **rare, complex and mostly chronic**. It's the combination of these factors that leads to an enormous scarcity of knowledge and expertise, allied to lack of resources and good practices, thereby creating huge obstacles to the performance of the necessary quality multidisciplinary and holistic care, that would combine health care and psychosocial support.

Care provided via social services and social policies over the course of a patient's life is instrumental for the quality of life of people living with a RD. This has been mentioned in several important EU documents referred above and compiled into the policy background and literature review concept paper 'Rare Diseases: Addressing the Need for Specialised Social Services and Social Policies'.

Specialised Social Services are a key requirement for individuals with complex, chronic conditions which need a multidisciplinary follow-up. These services include, amongst others, Therapeutic Recreation Programmes, Respite Care Services, Adapted Housing and Resource Centres. They can be specific to RDs as a whole, to a group of diseases or a single disease. They can also be directed to other target groups, such as mental or physical disabilities, having the possibility to integrate people living with a RD.

However, integrated psychosocial and educational support to patients and families is provided not only by Specialised Social Services but also by a set of social, health and education infrastructures and services, such as day-care facilities, home care, adapted schools, adapted work place/specialised workshops, personal assistants, Centres of Expertise, rehabilitation centres, hospitals and other health and social care facilities. All these services face challenges integrating patients with RDs.

Social services providers need to be made aware of RDs specificities in order to guarantee the quality of the services provided. Accurate information is indispensable as a basis for this.

Training of social services providers is an essential and efficient means of empowering professionals, families and patients **to face the challenges caused by RDs**, optimising the use of resources and creating synergies for progress. It will not only lead to better and more comprehensive care and greater autonomy of people living with a RD, but will also increase awareness and consequently reduce isolation and discrimination of people living with a RD.

2. METHODOLOGY FOR THE ELABORATION OF THE EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS

These guiding principles derive from the EUCERD Joint-Action workshop on 'Training for Social Services Providers'.

20 experts, from 11 countries, participated in this workshop, representing various stakeholder groups: EUCERD, training providers, Specialised Social Services, national authorities, national alliances and helplines for RDs, social workers and academia.

During the workshop, participants were introduced to some examples of training programmes and actively debated guiding principles. Discussion groups were composed of diverse stakeholder profiles and countries, in order to enhance diversity and quality of the debates.

A draft document was compiled in advance in collaboration with several experts representing the main stakeholders' groups. Workshop participants had a chance to comment on this draft before the workshop. The draft document and participants' comments were used as the starting point of the group discussions.

Participants were encouraged to comment on the guiding principles proposed and on possible additions and amendments to be applied. They were also asked to provide input concerning the type of document to be elaborated and its distribution plan, to ensure the best use of the document in terms of advocacy and of actual implementation of trainings.

The document was then reformulated in order to integrate the workshop's comments and was submitted to a new revision by the workshop groups' rapporteurs and by an additional multi-stakeholder adviser group.

3. TARGET GROUPS FOR THESE GUIDING PRINCIPLES

This document is directed to **Member States, RD experts, patient organisations and others involved in policy-making and advocacy** at European, national or regional levels, working within health, social welfare, education systems or other relevant fields. Patient organisations can benefit from using these principles to advocate for the improvement of holistic quality care for people living with a RD.

The **training programmes** to be implemented based on these principles **are intended for all social service professionals working at private or public, in-patient or out-patient, European, national or regional facilities**, such as: social services and structures, Centres of Expertise, hospitals, schools, local councils, etc.

These professionals are in direct contact with patients with RDs or are involved in the planning and logistics of the services provided. Such professionals include, amongst others: social workers, nurses, personal assistants and carers, psychologists, teachers, therapists, social rehabilitators, as well as administrative or reception staff. Other professionals might benefit from this type of training, depending on the Member State's organisation of services and care.

EUCERD JOINT ACTION GUIDING PRINCIPLES ON TRAINING FOR SOCIAL SERVICES PROVIDERS TO THE EUROPEAN COMMISION, MEMBER STATES AND ALL STAKEHOLDERS

MISSION, VISION AND SCOPE

1. **Developing training programmes is essential to ensure** that each Member State's social services providers are better prepared to provide care to people living with a RD, raising the **quality of services** offered and consequently **increasing patients' and families' quality of life**.

2. These guiding principles aim at collecting **good practice procedures** in order to **guide and inform authorities, services, patient groups, families and patients**.

3. Rather than aiming at promoting specialists in all RDs - which is likely unfeasible and costly - the implementation of these training programmes aims at **making sure that as many social service providers as possible are habilitated to properly care for patients** at local level and know where to find information, counselling and support to handle rare complex cases**.**

4. Trainings should **follow structures and requirements similar to those of other professional training programmes** existing at Member State level, in order to facilitate their establishment, accreditation and funding processes.

5. It is recommended that the training of social services providers is **implemented as part of a wider national cross-sector training programme for professionals** dealing with people living with a RD.

6. Trainings should be **appropriate and proportionate**:

    i. Trainings should be **adapted to the level of knowledge and to the needs** of each group of professionals;

    ii. Trainings should be **provided only to the extent that they are needed and relevant**.

7. In an adequate and proportionate manner, trainings should be updated throughout the professional path of the social service provider. **Continuity of training should be encouraged** and in some cases it might be beneficial to predict a maximum time span between trainings.

TRAININGS AND THE NATIONAL PLANS/STRATEGIES FOR RDS

8. When elaborating, evaluating or revising **National Plans/Strategies for RDs**, Member States should strive to **include a proposal for the training of social services providers,** in **cross-sector collaboration** between the Ministry of Health, the Ministry of Social Affairs, the Ministry of Education, Centres of Expertise, national Specialised Social Services and National Alliances for RDs.

9. **National authorities** and ministries of Health, of Social Affairs and of Education should do their utmost to be **involved in the promotion or implementation of these training principles and programmes.**

FUNDING, EVALUATION AND ACCREDITATION

10. **Funding mechanisms** for the training of social services providers **need to be adequate and long-term**.

11. Sustainable long term funding processes are needed, as training is likely to be necessary for the foreseeable future. It is then recommended that these **programmes are funded by the mechanisms normally used in each Member State to support training of professionals**.

12. It might be necessary to mobilise **specific public funding for the initial implementation phase**, until there is evidence of efficacy and integration into the regular funding framework for trainings in each Member State.

13. **The National Plans/Strategies for RDs** should include training programmes for social services providers and when possible, **allocate funds to the initial implementation phase**.

14. It is recommended that the **training assessment** should be **included in the internal and external evaluation of the services** providing care to people living with a RD.

15. It is recommended that a **system for accreditation** of the trainings is implemented, in order **to evaluate and guarantee the quality** of the contents shared, of the trainers involved and of the results obtained, taking into consideration that knowledge in the field of RDs is constantly being built.

COLLABORATIVE CROSS-SECTOR MULTI STAKEHOLDER HOLISTIC APPROACH

16. Trainings should be organised in **cooperation between all relevant parties** who can provide consultancy and valuable input such as the Centres of Expertise, University Hospitals and other expert health care providers, Orphanet's national teams, helplines for RDs, Specialised Social Services, patient organisations, patients and families**:**

    i. In the spirit of the [EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases](#), **Centres of Expertise** are essential partners in the **training of non-health care professionals and** in the **provision of accessible information adapted to the needs of health and social professionals**. Professionals from the Centre of Expertise should therefore be considered as trainers or invited speakers as well as advisors for the definition of training contents. The involvement of the Centres of Expertise in the training also contributes to raise awareness amongst medical experts for the role that they can play in supporting social service providers, for example, when completing the formularies needed for patient eligibility to social services or to social benefits;

    ii. Contact with **Orphanet's national teams** is encouraged from an early stage of the conception of the training programmes. These teams can be very helpful in **locating scientific information and resources** that will support the implementation of the programme;

    iii. **National help lines for RDs** are often habilitated to respond to enquiries from professionals, and frequently constitute a **huge source of information, both scientific and empiric/experience**

based knowledge, and of contacts that can be useful during the programme conception and implementation. It is therefore recommended that the help line team is involved in the training programme from an early stage;

iv. **Patient organisations,** including alliances of patient organisations, are fundamental partners in the **provision of information on patients' challenges and daily lives**. Frequently these groups have already identified a set of patient and families' needs and have supported families to address their challenges. Involving the patient group in the preparation of training and as speakers brings additional value to the contents and resources of the training;

v. **Families and patients** are one of the key sources of **information on daily struggles and needs** and even more so on patients' personalities, likes and dislikes, little routines, etc. Involving patients and families in the training, whenever possible, can be of great benefit to professionals, giving them those complementary pieces of knowledge which are so **important to know each patient** better and to provide the most **personalised care** possible;

vi. **International professional networks** of social services providers can also be a valuable support in **sharing good practices and knowledge**.

CONTENT AND ORGANISATION

17. Following the same principle of the Centres of Expertise and the European Reference Networks, it is recommendable that training **programmes are organised by therapeutic domains or [groups of] diseases**. Considering the large spectrum of RDs, trainings are surely more efficient when addressing specific disease profiles.

18. Trainings should **provide professionals with information and tools**, **prepare them to act and** be able to **establish a follow-up and bi-lateral communication system between trainers and trainees**.

19. Training programmes should reinforce the promotion of an **ethical and non-discriminatory attitude/policy** amongst professionals of the social sector towards people living with a RD.

20. Trainings should **promote RD specific tools** such as: Orphanet encyclopaedia, disability charts and rare disease core sets; helplines for RDs; EURORDIS InfoHub and other relevant tools developed by stakeholders involved in the RD movement, e.g. disability charts produced and validated at Member State level:

i. **Orphanet Encyclopaedia** is available in seven languages, is organised per disease, and is composed of abstracts, review articles by professionals, clinical guidelines and other resources representing an **invaluable source of scientific information** on the diseases, symptoms, genetic aspects, treatment, management,prevention and ongoing research;

ii. **Orphanet disability charts** are compiled per disease and include: a scientific abstract with medical information on the disease; **information on the consequent disabilities** and on measures to address these disabilities; information on patients' daily, familial and societal life (school, work, social life). These charts, currently only available in French, are a model of essential tools needed for the training of social services providers;

iii. Orphanet is developing **rare disease disability core sets** and an **online database crossing RDs and disability indicators**, in the framework of a project of <u>indexation of the functional consequences of each RD</u> with a thesaurus adapted from the <u>International Classification of Functioning, Disability and Health</u> (ICF). Core sets by RD are developed to provide a **greater knowledge on the incapacities** of people living with a RD **and their consequences in their daily lives and patients' life paths**, thereby supporting patients' evaluation of incapacity on which the compensation measures are based. Data for over 800 RDs will be published on Orphanet website, in seven languages, in the form of list of disabilities per disease, including their severity, frequency, temporality, and evolution. Data for other RDs will be progressively added afterwards. There will also be the possibility of extracting information for all diseases or per type of disability. This data is of great value for the training of professionals from the social field;

iv. Information and contacts from the **national helpline** and other relevant support services and organisations should be made available during the training, as an **information and support resource** which can be useful during the programme and beyond;

v. **EURORDIS InfoHub** has been developed to meet three basic needs: guidance on how to find quality RD information on the internet; a place where people can find a quality-driven selection of RD online resources; a specific tool which gives access to search results based on an index of affiliated patient organisation's websites. The portal, based on <u>quality criteria officially adopted by EURORDIS,</u> presents a series of <u>video tutorials</u> on how to find **quality information on the internet and a customised RD search engine**, which can be useful for trainers and trainees.

21. Training programmes' contents should attempt to include the following issues:

i. Information on the disease/group of diseases, the **medical consequences** and **treatments**;

ii. Information on the **disabilities generated,** the **psychosocial consequences** and the **consequences on patients' daily lives, life paths and autonomy**;

iii. The importance of the **multidisciplinary and cross-sector work**;

iv. **National and international sources of information and support**, including Orphanet, EURORDIS, local and national patient organisations, help lines and other RD specific tools;

v. Communication and **cooperation with health care** providers, professionals involved in **education and other professionals involved in patient care**;

vi. **Communication with patients and families**;

vii. **Patients' and families' rights** and relevant legal frameworks;

viii. The importance of **individual care**;

ix. The importance of **peer support**;

x. Patients' **psychological and emotional features**;

xi. **Adaptation of the environment** to the needs of the patient (home, school, work);

xii. **Security** measures;

xiii. **Other relevant issues for the specific target** group (neuropsychology, behavioural issues, nutrition, transition from childhood to adulthood, etc.).

22. Trainings should include **practical training** and preparation for real situations, via role playing or other methods deemed adequate.

23. Trainings should anticipate a model for **effective feedback and follow-up**, once the training is completed and the social service providers have to face real situations.

24. Trainings should make **the optimal use of information and communication technologies** in order to streamline resources and reach more professionals efficiently.

KEY DOCUMENTS

EJA WP6 Workshop on Training for Social Services Providers – Report
A full report of the workshop on 'Training for Social Services Providers' organised within the work package 6 of EUCERD Joint Action 'Working for Rare Diseases', on the 10-11th October 2013 can be consulted at http://www.eucerd.eu/wp-content/uploads/2014/03/WP6TrainingSSP.pdf.

Literature Review Concept Paper
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.eucerd.eu/wp-content/uploads/2013/03/EJA_Specialised_Social_Services_Paper.pdf.

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 [accessed 29 April 2014].

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 [accessed 29 April 2014].

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 [accessed 29 April 2014].

National Plans and National Conferences

Plan National Maladies Rares - Qualité de la prise en charge, Recherche, Europe: une ambition renouvelée: http://www.orpha.net/actor/Orphanews/2011/doc/Plan_national_maladies_rares.pdf [accessed 29 April 2014].

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 [accessed 29 April 2014].

Approaches to Disability and Handicap

International Classification of Functioning, Disability and Health (ICF):
http://www.who.int/classifications/icf/en/ [accessed 29 April 2014].

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 [accessed 18 September 2013].

Orphanet Disability Charts (examples):
Syndrome de Williams: https://www.orpha.net/data/patho/Han/fr/Handicap_Williams-FrfrPub145v01.pdf [accessed 22 January 2014].
Syndrome de l'X fragile: https://www.orpha.net/data/patho/Han/fr/Handicap_Xfragile--FrfrPub120v01.pdf [accessed 22 January 2014].
Syndrome de Cockayne: https://www.orpha.net/data/patho/Han/fr/Handicap_Cockayne-FrfrPub638v01.pdf [accessed 22 January 2014].

Standards of training for Social Service Providers

Global Standards for the Education and Training of the Social Work Profession, 2004: http://cdn.ifsw.org/assets/ifsw_65044-3.pdf [accessed 18 September 2013].