

# EUCERD JOINT ACTION WORKSHOP

## GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES



Zalau, 6-7 December 2012



Co-funded by  
the Health Programme  
of the European Union

# INTRODUCTION

The workshop was organised in the context of the ongoing activities of the [European Union Committee of Experts on Rare Diseases \(EUCERD\)](#), namely under the framework of the [EUCERD Joint Action \(N° 2011 22 01\)](#), Work Package 6 (WP6): '[Provision of Specialised Social Services and Integration of Rare Diseases into Social Policies and Services](#)'.

'Guiding Principles for Specialised Social Services' were the main subject of the workshop. The agenda was composed of several presentations followed by group and plenary discussions (see Appendix I – Agenda).

The workshop was attended by 28 experts, coming from 16 countries, representing the various stakeholder groups: EUCERD, Specialised Social Services, National Authorities, National Alliances, field social workers and academia (see Appendix II – List of Participants).

## Main Objectives

- To provide a forum to share information with EUCERD members and other interested parties on existent Specialised Social Services for people living with rare diseases;
- To incite debate on Guiding Principles for Specialised Social Services, consisting of main baseline guidelines for the implementation and functioning of 4 types of services: Respite Care Services (RCS), Therapeutic Recreation Programmes (TRP), Resource Centres (RC) and Adapted Housing Services (AH).

## Specific Questions Addressed

- What are the goals of the EUCERD Joint Action (EJA) and the specific goals of WP6?
- How are existing and experienced Specialised Social Services conducting their activities? Under which guiding principles?
- What are the existing funding opportunities for Specialised Social Services, under the framework of Structural Funds for Health?
- Which set of guiding principles shall be systematic for the set up and running of a Specialised Social Service integrating people living with rare diseases?
- What type of document should be produced to raise awareness for these principles and how can we make sure that principles will be known and followed at MS level?

## **The Starting Document**

A draft document has been compiled in advance in collaboration with some experienced services. This document was sent out to all participants at the beginning of November. Participants then had two weeks to comment on this first draft. Comments were compiled into a final draft, sent out to all participants one week before the workshop. This draft was used as the starting point of the group discussions.

The draft covered:

- Workshop's agenda and goals;
- General description of the EUCERD Joint Action and a detailed description of WP6 work plan and intended outcomes;
- Background information on Specialised Social Services and definition of types of services, based on the paper '[Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies](#)';
- Suggestions of 'Guiding Principles for Specialised Social Services';
- Bibliographic references.

## **Format of the Workshop and Methodology of Group Discussions**

The Workshop agenda was planned for a set of two complete days, starting from a more general background approach, narrowing down to the specifics of the actual 'Guiding Principles for Specialised Social Services'.

Part of Day 1 was dedicated to introductory issues such as the EUCERD Joint Action and WP6, and funding opportunities for services. The rest of Day 1 was dedicated to getting familiar with Specialised Social Services by visiting the work of the NoRo Centre on location and attending presentations by 4 invited services, one of each type: Respite Care Services (RCS), Therapeutic Recreation Programmes (TRP), Resource Centres (RC) and Adapted Housing (AH).

After becoming familiar with the workshop's context and concepts, participants spent Day 2 actively debating 'Guiding Principles for Specialised Social Services', in discussion groups first, and in plenary after.

The discussion groups were composed of diverse profiles and countries of origin, in order to stimulate discussions between participants facing different professional and societal realities, enhancing the quality of discussions and of the consequent conclusions.

The groups were asked to respond to a set of questions related to the principles presented in the draft. Participants were encouraged to:

- Comment on the guiding principles mentioned and on possible additions, deletions and merges to be applied;
- Define an order by which the final set of principles shall be presented;
- Suggest what type of policy document should result from the exercises performed during the workshop, to ensure the best sharing and use of the information collected.

## WORKSHOP REPORT

### **EUCERD Joint-Action 2012-2015, by Victoria Hedley (VH)**

VH's presentation lay the groundwork for the understanding of the context of the workshop by providing the wider context on the EJA, its background, goals, partners and 8 work packages. VH gave a clear notion of the general goals of the EJA as a whole, as well as of the goals of each work package, highlighting the several complementarities between different work packages. [Download the presentation.](#)

### **EUCERD Joint-Action WP6 'Specialised Social Services and Integration of RD into Social Policies', by Raquel Castro (RC)**

The presentation started by clearly stating the definitions of Specialised Social Services, in order to clarify from the beginning the scope of the work package's actions. RC presented the three-year project's timeline, highlighting its three main activities: identification and mapping of Specialised Social Services, training of Social Services Providers, and integration of Rare Diseases into social policies and services; clarifying that each activity represents the main focus of each of the project's years.

RC then focused specifically on progress made during the first year around the identification and mapping of services. Special emphasis was given to the presentation of the concept and literature review paper '[Rare Diseases: Addressing the Need for Specialised Social Services and Integration into Social Policies](#)' an advocacy tool that compiles the policy ground, different surveys, studies and literature reviews. The document also establishes short and clear definitions for each type of Specialised Social Service (TRP, RCS, RC, AH).

The new [EURORDIS website section on Specialised Social Services](#) was then presented in detail with special emphasis on the map of Specialised Social Services – containing over 20 services. A quick presentation of the website section was made in order to highlight other components, such as facts and testimonies related to the 4 types of services. The presentation finished with a clear reminder of the workshop theme and goals. [Download the presentation.](#)

### **Funding Opportunities for Specialised Social Services: Structural Funds for Health, by Jaroslaw Waligora (JW)**

JW, representing EU Health and Consumers General-Directorate, presented several EU funding opportunities which might be of interest for Specialised Social Services, including the European Regional Development Fund, Social European Fund and Cohesion Fund.

JW provided statistics and examples of how these funds have been applied to date. The discussion following the presentation went into more practical details of what can be available in each country and what influence each participant can have on the definition of the structural priorities in each country. For further clarification on these matters, JW supplied the workshop participants with the following complementary links:

- [http://ec.europa.eu/regional\\_policy/index\\_en.cfm](http://ec.europa.eu/regional_policy/index_en.cfm) – structural funds;
- [http://ec.europa.eu/regional\\_policy/manage/authority/authority\\_en.cfm](http://ec.europa.eu/regional_policy/manage/authority/authority_en.cfm) – funds per country;
- [http://ec.europa.eu/regional\\_policy/thefunds/instruments/jaspers\\_en.cfm](http://ec.europa.eu/regional_policy/thefunds/instruments/jaspers_en.cfm) – JASPERS program.

[Download the presentation.](#)

### **Ågrenska Respite Care Services, by Gunilla Jaeger (GJ)**

The Respite Care Services run by Ågrenska, in Sweden, serve a population of over 170 beneficiaries per year, integrating various groups of people living with particular RDs. GJ presented the history, the management and governance structure, as well as the services of this private non-profit service provider.

By working with homogeneous, fixed groups, under a programme with carefully planned contents developed by the staff after consulting professionals, existing literature and patients, Ågrenska's Respite Care Services aim to provide:

- Rest for parents and siblings while taking good care of the person living with a RD;
- Social development and refining social skills to the service beneficiary;
- An opportunity for the beneficiaries to meet others in same situation, learning from each other and establishing friendship relations;
- The chance to experience different recreational activities;
- The promotion of independence and tools to help prepare for adult life;
- The opportunity to exercise everyday practical tasks in a pro-learning and stimulating environment;
- The tools to prepare the person living with a RD to start becoming autonomous from parents. [Download the presentation.](#)

**Federation of European Williams Syndrome Therapeutic Recreation Programme, by Gábor Pogány (GP)**

GP presented the Therapeutic Recreation Programme of this Federation composed of Williams Associations from over 21 European countries. The Federation organises the camps in a different place every year. Since 2005, camps have been organised in such different countries as Norway, Hungary, Sweden, Germany, France, Italy and Spain.

The main goal of the camps is to empower young people living with Williams syndrome by motivating participants to extend the limits of their abilities, promoting fun and enjoyment in an informal, international environment that privileges solidarity and promotes a culture of non-discrimination and access to equal opportunities. During the camps, participants are also provided with 5-10 days of intensive therapy of habitation/rehabilitation.

GP concluded his presentation by highlighting the benefits of Therapeutic Recreation Programmes:

- For the children/youth: increase in independence and well-being; fun; overcoming of barriers; reinforcement of self-esteem; participation in essential development programmes providing leisure and relaxation side-by-side with rehabilitation;
- For the whole family together: learning from each other; exchange of experiences and good practices; learning of 'survival techniques' and skills; access to entertainment, recreation activities, reducing anxiety and providing emotional support. [Download the presentation.](#)

**Frambu Resource Centre, by Lisen Mohr (LM)**

Frambu Resource Centre, located in Norway, serves over 28 000 beneficiaries every year affected by about 100 different diagnoses. This Resource Centre is run by a private trust and financed by the Norwegian state budget. The service was presented by LM, who described the history of the service as well as some facts on Frambu and its management structure.

Frambu offers services complementary to medical and municipality services. The Centre currently provides residential courses, communication and documentation on diagnosis and outreach activities in the beneficiaries' local communities, guiding and training beneficiaries, families and professionals. The Centre also promotes research projects and organises summer camps.

The service provides a platform through which it is possible for beneficiaries and their families to meet other people facing similar situations, promoting a positive approach and experience.

LM concluded the presentation by recalling that having a rare condition is like finding oneself in a different world and having to stay there, enhancing the importance of having services that provide tools to cope with this reality and promote the quality of life of people living with a RD. [Download the presentation.](#)

### **Adapted Housing for Prader Willi, by by Susanne Blichfeldt (SB)**

SB started by providing information on Prader-Willi syndrome and the specific challenges it generates. To better explain the framework of the Adapted Housing services, SB provided an overview of the Danish system concerning housing for people with physical and/or mental disabilities. In Denmark, these adults have the right to live in their own apartment or in houses for 5-8 people, receiving support from trained staff.

Group homes for Prader Willi syndrome started in 1988, under an experimental model focused on independent living. Several difficulties arose due to the disease symptoms. The model was then readjusted by establishing a control of beneficiaries' diet and food intake, requiring the cooperation of staff and families.

There are currently 10 group homes for Prader Willi syndrome in Denmark, housing 70-80 adults altogether. These services employ trained staff, according to the inhabitants needs, such as special teachers and social workers. Rents are paid by beneficiaries' own pensions received from the state due to their medical condition. The municipalities or regional authorities cover staff and general house-running logistical costs.

SB concluded by providing examples of several of the group homes, illustrating their activities and facilities. [Download the presentation.](#)

### **NoRo Centre, by Dorica Dan (DD)**

NoRo Resource Centre is a patient run service which has been the host of this workshop. Workshop participants had the opportunity to have a guided tour to the facilities and to witness some of the therapies and activities live. DD then presented the service, complementing the live visit.

NoRo Centre is a result of the joint effort of several Romanian and Norwegian partners. NoRo is a pilot reference centre for RD, promoting a platform of debate, an e-University, Help Line and the exchange of best practices. The service develops training resources for professionals such as rehabilitation teachers, socio-educative animators, arts therapists, nurses, personal assistants of severely disabled people, etc. All the training courses are authorised and accredited by the Ministry of Labour and Ministry of Education as training programmes for adults. The centre has also an accredited training course for doctors –



Management of the RDs, accredited by the Doctors Collegium with 16 credits CME. The Centre is accredited both for medical and social services. The funding of the service is still a challenge. It is provided by the Local Council Zalau, the County Council Salaj, the Ministry of Work and the Ministry of Health.

NoRo develops programmes of training for independent life with groups of young people with RD. In parallel the service runs daily activities of personalised intervention, educational, recreational and social activities, vocational guidance and counselling for parents. The service also assures the development of a patient's registry and of several researches in the social field. [Download the presentation.](#)

### **Outcome of the Workshop**

As a result of the discussions held, a final document on 'Guiding Principles for Specialised Social Services' is to be compiled and disseminated among EJA partners, EUCERD at large, Workshop attendees, EURORDIS members and the general public, via [EURORDIS](#) and [EUCERD](#) web pages.

### **Next Steps**

During the workshop, several participants manifested their appreciation for the document resulting from the discussions and emphasised that it will have an unquestionable value at the National Level. The document will be presented at the EUCERD meeting in June 2013.

## APPENDIX

### I) AGENDA

#### DAY 1: Thursday 6 December

09:30 Welcome to all participants, *by Dorica Dan, Project Leader, EURORDIS*

10:00 Presentation of the EUCERD Joint Action, *by Victoria Hedley, EUCERD Joint Action Assistant Manager, Newcastle University*

10:30 Coffee Break

11:00 Presentation of the WP on Specialised Social Services and Integration of RDs into Social Policies, *by Raquel Castro, Social Policies Manager, EURORDIS*

11:30 Visit of the NoRo Resource Centre: live contact with the activities and benefits of a Specialised Social Service

12:30 Lunch

14:00 Funding Opportunities for Specialised Social Services: Structural Funds for Health *by Jaroslaw Waligora, EU Health and Consumers General-Directorate*

14:30 Presentations by several invited Specialised Social Services (30min/each):

Respite Care Service – *Ågrenska (Sweden), by Gunilla Jaeger, Operations Team*

Therapeutic Recreation Programme – *Gábor Pogány (Europe), Federation of European Williams Syndrome*

Resource Centre – *Frambu (Norway), by Lisen Mohr, Communication and Documentation*

Adapted Housing - *Danish PWS Association, by Susanne Blichfeldt, Pediatric Consultant, Medical Advisor*

16:30 Coffee Break

17:00 Overview of draft document on Guiding Principles for Specialised Social Services

18:00 End of the first day

**DAY 2: Friday 7 December**

9:30 Wrap up from the first day, *by Raquel Castro, Social Policies Manager, EURORDIS*

10:00 Coffee Break

10:30 Group discussions on Guiding Principles for Specialised Social Services

12:30 Lunch

14:00 Presentation of conclusions in plenary, *chaired by Dorica Dan, Project Leader, EURORDIS*

14:45 Discussion of conclusions to reach consensus, *chaired by Dorica Dan, Project Leader, EURORDIS*

15:30 Coffee Break

16:00 Wrap-up of workshop and future plans, *by Raquel Castro, Social Policies Manager, EURORDIS*

16:30 End of the second day

**II) LIST OF PARTICIPANTS**

<b>Name</b>	<b>Authority/Institution Represented</b>	<b>Country</b>
Anica Jezic	AUTHORITIES - Croatia Mo Social Politics and Youth	CROATIA
Birutė Kavaliauskienė	EUCERD - MoH (nominated by EUCERD)	LITHUANIA
Boncz Bea	SERVICES - TRP - Hungarian Williams Syndrome Association	HUNGARY
Borut Peterlin	EUCERD	SLOVENIA
Cristina Rusu	ACADEMIA - Orphanet Romania	ROMANIA
Danijela Szili	SERVICES - TRP - Rett Syndrome Fountation Hungary	HUNGARY
Dodo Agladze	EUROPLAN/NA	GEORGIA
Dóra Aczél	SERVICES - TRP - Yuppi Camp	ROMANIA
Dorica Dan	EURORDIS/EUROPLAN/NORO	ROMANIA
Gabor Pogany	SERVICES - TRP - European Williams Federeation	HUNGARY
Gunilla Jaeger	SERVICES - RCS - Ågrenska	SWEDEN
Harrie Seeverens	EUCERD	NETHERLANDS
Isabel Peña-Rey	EUCERD	SPAIN
János Sándor	EUCERD	HUNGARY
Jarek Waligora	DG-SANCO	LUXEMBOURG
John Dart	FIELD WORK/BOD	UNITED KINGDOM
Lisen Julie Mohr	SERVICES - RC - Frambu	NORWAY
Marta Fonfría	SERVICES - RCS - CRE Enfermedades Raras	SPAIN
Monica Hercut	AUTHORITIES - Ro. MoH	ROMANIA
Mónika Demcsik	FIELD-WORK - Social Expert	HUNGARY
Natālija Pīlpa	EUCERD – MoWelfare (nominated by EUCERD)	LATVIA
Raquel Castro	EURORDIS	FRANCE
Renza Barbon	EUROPLAN/NA	ITALY
Stefania Porchia	ACADEMIA - Expert in Socio-Health issues	ITALY
Susanne Blichfeldt	SERVICES - AH - Group Homes PW Denmark	DENMARK
Victoria Hedley	EUCERD – EJA – UNEW	UNITED KINGDOM
Vlasta Zmazek	EUROPLAN/NA	CROATIA

### III) BIBLIOGRAPHY

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>

#### 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](http://ec.europa.eu/health/ph_threats/non_com/docs/rare_com_en.pdf) [accessed 29 July 2012].

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 July 2012].

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 July 2012].

#### National Plans

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](http://www.orpha.net/actor/Orphanews/2011/doc/Plan_national_maladies_rares.pdf) [accessed 07 November 2012].

#### Other studies and Surveys

Agazio, E. *et al.*, 2005. Accessibility and quality to health social services in Italy for the patients with rare diseases: the opinion of associations. *Annali di igiene : medicina preventiva e di comunità*, Mar-Apr;17(2):121-8.

Avellaneda, F. *et al.*, 2007. Sociosanitary impact on patients with rare diseases (ERES study). *Medicina clínica*, Nov 10;129(17):646-51.

Békési, A. *et al.*, 2011. Health-related quality of life changes of children and adolescents with chronic disease after participation in therapeutic recreation camping program. *Health and quality of life outcomes*, Jun 14;9:43.

Connecticut Department of Children and Families Mental Health Division. 2000. *Practice Standards for Respite Care Programs*.

Davies, S. and Hall, D., 2005. 'Contact a Family': professionals and parents in partnership. *Arch Dis Child*, 90: 1053-1057.

EURORDIS, 2009. *The Voice of 12,000 Patients*. Paris: EURORDIS.

Gaite, L. *et al.*, 2008. Needs in rare diseases during paediatric age. *Anales del sistema sanitario de Navarra*, Suppl 2:165-75.

Garcia, H. *et al.*, 2009. *Estudio sobre situación de Necesidades Sociosanitarias de las personas con Enfermedades Raras en España, Estudio ENSERio*. Madrid: FEDER – Federación Española de Enfermedades Raras.

Genetic Interest Group, 1999. *Achieving integrated services and support for families with rare genetic disorders*. London: Genetic Interest Group.

Griffith, J. *et al.*, 2011. "You have to sit and explain it all, and explain yourself." Mothers' experiences of support services for their offspring with a rare genetic intellectual disability syndrome. *Journal of Genetic Counselling*, Apr; 20(2):165-77.

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

Hernandez, VR., Selber, K. and Tijerina, M., 2006. Visioning Family-Centered Care in Genetics: What Parents and Providers Have to Say. *Journal of Genetic Counselling*, 15 (5): 349–360.

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

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.

McGarvey, B. and Hart, C., 2008. *An investigation into the social support needs of families who experience rare disorders on the island of Ireland (102 pages)*. Dublin: RehabCare

McGarvey, B. and Hart, C., 2009. *An Investigation into the social support needs of families who experience rare disorders on the island of Ireland*. Dublin: RehabCare.

Merriman, B. and Canavan, J. 2007. *Towards best practice in the provision of respite services for people with intellectual disabilities*. Dublin: HSE.

Merriman, B. and Canavan, J., 2007, *Towards best practice in the provision of respite services for people with intellectual disabilities and autism*. HSE/NUI, Galway Child and Family Research Centre.

<http://www.npsa.ie/Documents/RespiteResearch/respiteresearch.pdf> [accessed 29 July 2012].

Order no. 383 of June 6, 2005, *approving the general quality standards for social services and how to evaluate suppliers' performance*; Issued by: Ministry of Labour, Social Solidarity and Family Romania, Published in: Official Gazette no. 709 of August 5, 2005

Perrin, J., 1999. What about us? — Brothers and sisters of children with a physical disability express their views in groups. *Irish Social Worker*, 17 (1-2): 11-13.

Redmond, B., Bowen, A. and Richardson, V., 2000. *The needs of carers of fragile babies and young children with severe developmental disability*. Dublin: Centre for the Study of Developmental Disabilities, University College Dublin.

RehabCare. Unpublished. *Admission in Respite Care Guidelines*.

*Respite Services Specialist Study Group Report* (2006, confidential report)

Scottish Executive. *National Care Standards: Short breaks and respite care services for adults*. Scottish Executive

South Carolina Department of Disabilities and Special Needs, 2001. *Respite Standards*.

Swedish Association of Rare Disorders, 2002. *With Focus on Daily Life*.

Van Nispen, R., Rijken, P. and Heijmans, M., 2002. *Living with a Rare Chronic Disease: Experiences of patients with care and in daily life*. The Netherlands: Nivel.