



GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

April 2013



Co-funded by
the Health Programme
of the European Union



“Placing one foot in front of the other, I've climbed to higher lengths. Reaching beyond my own limitations, to show my inner strength. No obstacle too hard, for this warrior to overcome. I'm just a man on a mission, to prove my disability hasn't won.”

Robert Michael Hensel, Born with Spina Bifida
Guinness World Records holder for the longest non-stop wheelie in a wheelchair (6.178 miles)

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GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

1) INTRODUCTION

1.1 Background

A disease is defined as rare in the European Union (EU) when it affects no more than 5 in 10.000 people. It is estimated that between 5.000 and 8.000 distinct rare diseases exist today, affecting between 6 % and 8 % of the population in the course of their lives. Although each rare disease is individually characterised by low prevalence, the total number of people in the EU who are or will at some point be affected by a rare disease is between 27 and 36 million. Specialised Social Services represent an important resource to improve the quality of life of these millions of people.

Specialised Social Services are mentioned in the 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 (November 2008), in the Council Recommendation on an Action in the Field of Rare Diseases (June 2009), in EUROPLAN I final report recommendations based on the 15 EUROPLAN National Conferences (2010-2011), as well as in other important European surveys and studies. This policy background and additional literature review have been compiled into the concept paper '[Rare Diseases: Addressing the Need for Specialised Social Services and Social Policies](#)'.

Specialised Social Services include [Therapeutic Recreation Programmes](#), [Respite Care Services](#), [Adapted Housing](#) and [Resource Centres](#). These services can be specific to rare diseases, to a group of diseases or to other target groups, such as people with mental or physical disabilities.

The activities of the [EUCERD Joint Action Working for Rare Diseases \(EJA\)](#) allow a specific focus on these Specialised Social Services, via its [Work Package 6 \(WP6\)](#) dedicated to 'Specialised Social Services and Integration of Rare Diseases into Social Policies and Services'.

The following Guiding Principles are directly derived from the [workshop on 'Guiding Principles for Specialised Social Services'](#), organised in December 2012, in the scope of the first task of EJA WP6, dedicated to: i) identification and mapping of existing services and identification of good practices; ii) organisation of country visits to establish direct contact with services; iii) description of on-going initiatives and publishing on the web; iv) development of guiding principles.

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. The [workshop agenda](#) was planned to allow two complete days of activity, starting from a more general background approach, narrowing down to the specifics of the actual 'Guiding Principles for Specialised Social Services'.

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.

A draft document was compiled in advance in collaboration with some experienced services. Participants had a chance to comment on this draft and received a final draft version one week

before the workshop. This draft document 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.

During the workshop discussions, participants were encouraged to: comment on the guiding principles proposed 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.

1.2 Scope of Guiding Principles for Specialised Social Services

Although services might be specifically developed for rare diseases, more commonly, Specialised Social Services will target specific disease groups or specific mental and physical disabilities. The following Guiding Principles are important to make sure that every service can access quality guidelines which enhance the capacity of that service to integrate people living with rare diseases, making sure that all current and future resources are optimised, to the benefit of both patients and society at large.

Rather than be a definite model for specialised social services, these principles aim to inform good practice standards in the development and on-going activities of Specialised Social Services integrating people living with rare diseases.

The principles are designed to include the baseline guidelines in the broadest possible sense. Nonetheless, it is anticipated and understandable that some Specialised Social Services operating periodically – such as most of the Therapeutic Recreation Programmes – may not require the full application of the following principles and shall therefore apply them partially and pragmatically, within their frameworks and resources. It is also likely that each country will have additional principles that need to be applied in accordance with national or local realities.

Specialised Social Services that can prove to respect the following guiding principles will be meeting international quality standards and might use this compliance to obtain accreditation by their respective national competent authority. The accreditation will certify their competence, impartiality and reliability in terms of their capacity to deliver quality results. This will increase both beneficiaries' and national authorities' trust in the services provided, being also a possible tool in accessing funding opportunities. In the event of the country having no accreditation system for Specialised Social Services, a self-evaluation process in respect to these principles will in itself be a valuable tool to access and improve the quality of the services provided.

1.3. Target Groups for these Guiding Principles for Specialised Social Services

These principles shall be useful for Member States and their respective Health and Social Authorities, Specialised Social Services funders and providers, Centres of Expertise, patient representatives, patients and families.

2) GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES

Specialised Social Services are important to improve the global social care of patients, building their pathways through information, counselling, empowerment, leisure, and other support measures, assuring respect for patients' rights and promoting the autonomy of patients and carers and their integration in the community.

Before exploring in depth the different principles, there are three core statements that shall be kept in mind:

- **Beneficiaries must always play a central role in shaping the service.** They will often represent the greatest expertise as, due to the infrequency of rare diseases, knowledge about the diagnosis among medical staff and other support professionals tends to be scarce;
- **Guidance of the professionals working in the services is of great importance.** Caregivers are obvious collaborating partners in this respect, but additionally Specialised Social Services staff should be offered qualified supervision and guidance from a qualified team member or consultant;
- **Specialised Social Services are an important liaison service** between medical, administrative and social institutions, and patients/families/carers. The service should be as prepared as possible to accomplish this important mission.

A set of principles of excellence is proposed below.

1) Rights and Personal Identity

Specialised Social Services shall protect and promote the rights of beneficiaries in terms of equal opportunities, equal treatment, equal participation, self-determination, autonomy and personal dignity.

- Specialised Social Services shall facilitate equal access to services for people living with rare diseases, without discrimination of sex, age, religion, ethnicity, nationality or area of residence;
- Services shall establish criteria for equitable eligibility and admission, depending on the types of services provided, on the needs of each patient and on the available resources;
- Specialised Social Services shall define procedures and internal regulations which respect and support the rights of the beneficiaries in terms of equality of opportunities namely in relation to the access of Specialised Social Services;
- Whenever possible, services shall develop systems that enable assistance to beneficiaries living in remote areas, ensuring access to services for all targeted people living with rare diseases regardless of their area of residence. Models such as Frambu's domiciliary visits might serve as inspiration here.
- When Specialised Social Services are not specific to rare diseases, they shall adapt their practices and working methods to be able to adjust to the specific care needs of beneficiaries with rare conditions.

2) Person/Family Centeredness

Specialised Social Services shall adjust services according to the needs of each beneficiary living with a rare disease, developing individualised intervention plans for each of these complex cases.

- Each person and each family is unique and so are their needs. Services shall be reasonably flexible and responsive to the individual needs of each beneficiary living with a rare disease and his/her family;
- Beneficiary and family-centred principles for the development of the service, its policies, programmes, the design of facilities, and staff practices shall always be taken into account. This will include consultation with beneficiaries and families in all main aspects of the development of the service;
- Beneficiaries and their families have specific social needs which may vary at different stages of their lives. Specialised Social Services shall endeavour to offer counselling and support in pursuing additional social benefits beyond the immediate scope of the services provided, such as access to adequate education, support with the transition from childhood to adulthood, access to work and professional integration and access to independent living support structures.

3) Holistic, Comprehensive, Integrated Approach

Specialised Social Services integrating people living with rare diseases shall keep in mind that the multi-expression of RDs requires a holistic, comprehensive approach to the provision of services for beneficiaries and their families.

In order to provide such comprehensive support to each user, Specialised Social Services must be sure to consult other organisations and receive input from multidisciplinary teams.

To achieve this, services shall develop multilateral partnerships to harness the contributions of all potential partners and stakeholders, including Centres of Expertise/Medical Institutions, patient organisations, the local community, social workers, schools/employers and other organisations of interest.

- In the interest of the beneficiary, the Specialised Social Services may submit the beneficiary's information to other partners involved in consulting/handling the case, with due consent from the beneficiary or his/her legal representative, and in compliance with the national data protection legislation;
- Specialised Social Services shall review and evaluate the effectiveness of their services in relation to the degree of integration/reintegration and/or quality of life of the beneficiary, in accordance with the objectives set out in the individual intervention plan.

4) Governance Structure

Specialised Social Services shall be based on a democratic and inclusive governance structure, including a managing board and, when possible, an advisory committee including representatives of all fields of interest involved in patients' and families' care:

- Each Specialised Social Service shall ensure that its managing board and/or advisory committee include a reasonable number of patient representatives, who can speak on behalf of service beneficiaries and their families, expressing their specific needs;
- The managing and/or advisory body shall also include professionals from the medical field (when possible, Centres of Expertise) and from the social field, ensuring that the senior management structure of the service is composed of experts from all areas of the field of patient and family care;
- Services shall promote beneficiaries' – or their representatives' – active involvement at all organisational levels of the Specialised Social Service and their participation shall be considered as part of existing evaluation and accreditation procedures.

5) Organisation and Administration

Specialised Social Services shall aim at developing efficient organisational processes and effective internal procedures facilitating the provision of quality social services.

- Specialised Social Services shall define their policies and objectives for a period of three to five years, included in a strategic plan, developed in accordance with applicable law and with the assistance of several stakeholders;
- Services shall define an activity plan for each year, stating clear service and quality indicators to achieve;
- Specialised Social Services shall develop and implement internal regulations including registration and admission procedures, care guidelines, a strategy for the mediation of conflicts and settlement of claims presented by beneficiaries, their families or legal representatives;
- Specialised Social Services shall communicate the strategic plan, the activity plan and their internal regulations to staff, to beneficiaries and their families, to the community and to other relevant stakeholders;
- Specialised Social Services shall maintain regular internal and external communication activities to disseminate information on their services, their strategy, and their good practices;
- Services shall ensure that all documentation on the service, its strategy, its admission processes and operating rules, and its good practices, is updated, accurate and easily accessible by the management structure, the staff, beneficiaries/families, and any other partners or visitors to the service;

- Services shall guarantee that each beneficiary's case file is stored/filed in adherence of data protection guidelines/laws. This chart will include not only the admission dossier, but also all records of incidents/events kept in the beneficiary's chart for internal follow up;
- A service contract shall be established, in an accessible format, to outline the terms and conditions of stay and service benefit. Patients and families shall receive information on this contract along with the document itself on admission. This document shall serve both to inform families and protect services, ensuring all information is timely and clearly shared;
- Services shall aim at the best quality follow-up, ensuring that any issues which occur are included in the evaluation process and are addressed within a perspective of continuous improvement of services and care provided.

6) Evaluation and Continuous Improvement of Quality

Specialised Social Services shall develop a systematic approach to the improvement of quality of the services provided, as well as methodologies for monitoring the implementation of new programmes, with the main goal of ensuring quality, stability, continuity, initiative, competence among staff and a good communication flow with people living with rare diseases and their families and carers.

- Specialised Social Services shall communicate their clear mission and goals as well as performance indicators in order to promote transparency and to facilitate processes of evaluation;
- Services shall promote the regular monitoring of the service indicators, in comparison with upfront expectations and measures stated in the strategic and activity plans of the service;
- Services shall be submitted to self-evaluation, beneficiary evaluation and external evaluation/audit, on a regular basis, using systems that allow comparison of data and evolution over time. These evaluations shall be performed using the most convenient formats for the service and the involved parties;
- Specialised Social Services shall conceive a mandatory training programme – with an element dedicated to the specificities and challenges of rare diseases - to be completed by all staff, promoting a culture of continuous learning and development in the service;
- Services shall develop a training programme for volunteers, trainees and any other temporary staff, ensuring a rapid integration into the service and its good practices while guaranteeing the quality of the services provided;
- Specialised Social Services shall make available a formal complaint process which is clear and accessible and in accordance with applicable law, and shall promote an appropriate complaint follow up, within the framework of the process of continuous evaluation and improvement of the service, ensuring that the beneficiary's complaint is handled in the best possible way.

7) Connection to Centres of Expertise/Medical Institutions

Considering the specificities of rare diseases, Centres of Expertise represent an excellent ally to the Specialised Social Services' teams, being the medical institutions that concentrate greater health care expertise for these rare and debilitating diseases. Specialised Social Services shall be prepared to consult with these Centres of Expertise whenever integrating a person living with a rare disease. To facilitate that process, a list of the country's Centres of Expertise shall be kept and regularly updated at the service.

When integrating a person living with a rare disease, Specialised Social Services shall be bi-directionally linked to Centres of Expertise, ensuring the complementarity of the services and the multidisciplinary competencies/skills in order to serve the specific medical, rehabilitation and palliative needs of people living with rare diseases and to best handle rare complex cases.

In the spirit of the EUCERD Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases and of the EUCERD Recommendations on European Reference Networks for Rare Diseases, Specialised Social Services shall cooperate with Centres of Expertise in order to:

- Guarantee that patients are followed by a multidisciplinary team;
- Ensure that patients are referred to the Specialised Social Service by their Centre of Expertise;
- Involve the Centre of Expertise in the initial evaluation of the beneficiary and in the conception of the individual plan;
- Evaluate the possible role of the Centre of Expertise in the elaboration of the service's guidelines, in consultation with the team responsible for developing the clinical best practices of the Centre of Expertise;
- Involve the Centre of Expertise in the training of non-health care professionals working at the Specialised Social Service;
- Engage the Centre of Expertise in the production of information materials adapted to the specific needs of beneficiaries, families and carers.

8) Admission Procedures and Individual Assessment

Specialised Social Services shall develop complete admission and initial evaluation procedures, ensuring the collection of all essential data to perform a proper evaluation of beneficiary's needs and, simultaneously, facilitating the provision of all essential information about the services and the conditions of their provision to patients and families.

- Specialised Social Services shall provide accessible information about the service available for beneficiaries and families prior to the stay/evaluation and admission in the service, which should include the following: aims of the service; admission procedures; costs; rights and responsibilities of the beneficiary; risk assessment procedures; and complaints procedures;
- An initial evaluation shall be performed in order to assess whether the Specialised Social Service is able to accept the beneficiary and to establish the needs of this particular patient and family/carers. This initial evaluation shall be performed in cooperation with the Centre of Expertise (whenever existing) and with any relevant patient groups or other stakeholders working with the disease of the patient in question;

- Documents used in the process of initial evaluation and admission process shall include: first request, admission file, initial evaluation report, socio-medical assessment file, individual intervention plan, intervention report;
- If the Specialised Social Service corresponds to the needs of the beneficiary and his/her family/carers, a complex, deeper evaluation shall be performed by a multidisciplinary team and a personal intervention plan shall be developed. Services shall then be provided based on this individual intervention plan;
- In the event that the Specialised Social Service does not correspond to the needs of that specific person living with a rare disease, an alternative service shall be recommended;
- When admitting the beneficiary, a service contract shall be established between the Specialised Social Service and the beneficiary and his/her family/carers, in a clear and accessible format that outlines the terms and conditions of a stay/benefit;
- The individual intervention plan document shall include: the desired outcomes of the intervention; identification of activities targeted to achieve these outcomes; the services needed to support the proposed activities; anticipated timeframes for accomplishing outcomes and list of staff and external experts, if any, responsible for implementing the individual intervention plan.

9) Training of Staff and Volunteers

Services shall develop an internal training programme to be completed by all staff and volunteers, promoting a culture of continuous learning and development in the service, and ensuring that all staff/volunteers access adequate training, information and tools to be able to provide the best possible care to each beneficiary. This training shall be on-going, to continuously address the needs of beneficiaries over time.

- The training programme shall instil a familiarity with and understanding of the principles in the present document and other good practices considered necessary, concerning the specific services provided and the target population (age and diagnosis groups);
- The training programme shall also include a component on handling the emotions of beneficiaries and their families, ensuring that all staff/volunteers are well prepared to deal with the specific feelings of patients and families attending the service;
- This training shall also prepare staff/volunteers to deal with eventual frustrations resulting from the follow up of patients with serious, debilitating mental or physical handicaps;
- Each beneficiary's integration might require additional training to deal with the specific needs of this patient and his/her family/carers. The training programme shall anticipate this, making sure to include a section on sources of information and consultancy in the event of admission of beneficiaries with needs never before handled by the service;
- The training programme shall include a module on specificities and challenges faced when handling people living with rare diseases, preferably prepared in cooperation with the corresponding Centre of Expertise/Medical Institution.

10) Rare Diseases and Health Care Needs

Due to the infrequency of rare diseases, information on these conditions and patients'/families' needs tends to be scarce. This often results in a need to collect some additional preparatory information, in close cooperation with families, health-care specialists (Centre of Expertise, whenever existing) and support organisations, working directly with the concerned diagnosis or with the specific beneficiary.

Considering the specificity of rare diseases, Centres of Expertise represent an excellent ally to the Specialised Social Services' teams, as the medical institutions that concentrate greater health care expertise for these rare and debilitating diseases. Specialised Social Services shall be aware of the importance of the role of Centres of Expertise and will be prepared to consult with them whenever integrating a person living with a rare disease.

The issues presented below have particular relevance when considering Specialised Social Services providing residential programmes. All the subjects below shall be assessed in the initial evaluation, to be sure that the service can indeed meet all the needs of the beneficiary:

- People living with rare diseases might often need special equipment or technologies in order to meet the beneficiary's medical and comfort needs;
- Beneficiaries with rare diseases might require a close daily follow up. Experts on multiple disabilities might need to be present or within reach, in order to manage day-to-day needs and to be on call for the management of any unexpected/serious event;
- Rare disease patients may need to be administered special medications during their stay at the service which they might be trained to take themselves or which might need to be administered by trained staff. All administration of medication shall be performed with respect for the independence of an individual taking their own medication or in adherence to procedures for safe administration, in line with professional guidelines obtained from health/treatment specialists following the patient;
- For several rare conditions, special dietary/nutritional needs must be considered and planned before the start-up of every programme. The service shall then be prepared to consult with the family and health-care and/or nutrition specialists accompanying each specific family and/or diagnosis before approving their menu.

APPENDIX

APPENDIX I: EUCERD JOINT ACTION WORKING FOR RARE DISEASES 2012-2015

Rare diseases are a priority area for action in the European Commission's Public Health Programme (2008-2013). The European Union Committee of Experts on Rare Diseases (EUCERD), formally established via the European Commission Decision, 30 November 2009, is mandated to assist the European Commission (EC) in formulating and implementing the Community's activities in the rare disease (RD) field, and to foster exchanges of relevant experience, policies and practices between the Member States (MS) and stakeholders.

EUCERD has now launched a Joint Action 'Working for Rare Diseases' (EJA), funded by DG Sanco, engaging one coordinating partner and seven associated partners. The EJA is composed of 8 work packages addressing different issues and current challenges around RDs.

EURORDIS is responsible for the work package 6, dedicated to 'Specialised Social Services and Integration of RDs into Social Policies'.

The EJA will specifically address the following priority areas: visibility and recognition of RDs; development and dissemination of knowledge on RDs from specialised research, to the support of healthcare professionals and the empowerment of people living with rare diseases (PLWRDs); improvements in access to quality services and care, from diagnosis, to social support and innovative therapies.

To achieve its aims, the EJA is constructed in such a way as to add value to the many investments which have already taken place at EU level, by building on the achievements of projects that have received EU funding in the past years. The EJA will comprise five main areas of work:

- The implementation of plans and strategies for RDs at national level;
- The standardisation of the RDs nomenclature at international level;
- The mapping of Specialised Social Services and integration of RDs into mainstream social policies and services;
- The leveraging of the value of EU networking for improving the quality of care for PLWRDs;
- The integration of RDs initiatives across thematic areas and across MS.

The EJA work is supported by a variety of methodologies, including literature reviews, questionnaires or Delphi procedures, dissemination of information and web based exchange platforms, consensus workshops and generation/validation of specific recommendations.

The expected outcome is an integrated strategy for the implementation of RD policies through the exchange of experience between national health authorities already involved in RD policy definition/implementation and via a series of recommendations from the EUCERD, clearly communicated to national policy makers, patient organisations and learned societies.

APPENDIX II: EUCERD JOINT ACTION WORK PACKAGE 6: SPECIALISED SOCIAL SERVICES AND INTEGRATION OF RARE DISEASES INTO SOCIAL POLICIES AND SERVICES

The work of WP6 of EUCERD Joint Action 'Working for Rare Diseases' (EJA) focuses on the different lines of work specified below.

Specialised Social Services

Facilitating online access to information on existing services, sharing good practices and guidelines for:

- Therapeutic Recreational Programmes;
- Respite Care Services;
- Adapted Housing Services;
- Resource Centres.

Integration of Rare Diseases into Social Policies and Services

- Training: describing training needs for social services providers and identifying/sharing existing practices in this field;
- Social guidelines: identification of existing social guidelines; dissemination of methods, tools, and validation processes of good practices.

Work Package's Main Activities

- Collection of contacts and research on existing Specialised Social Services;
- Update of online information on Specialised Social Services;
- Presentations at European conferences and other relevant events gathering patient representatives (such as National Alliances and European Federations for rare diseases) or other relevant stakeholders;
- Country Visits to familiarise with existing Specialised Social Services and assess good practices;
- 3 Workshops on Specialised Social Services, Training of Social Services Providers and Social Polices, in December 2012, October 2013 and October 2014, respectively;
- Elaboration of the EUCERD report on guiding principles for social care in RDs / draft of EUCERD Recommendations in the social field.

Work Package's Outcomes

- Dissemination of information on different types of Specialised Social Services and their benefits for the RD community and for the polyhandicap community;
- Increased awareness of the need for Specialised Social Services;
- Increased visibility of existing Specialised Social Services at international and national levels, among key policy makers, PLWRDs, researchers and physicians;
- Dissemination of information on good practices and guidelines for implementing and running Specialised Social Services;

- Provision of information on existing services which constitute case studies;
- Increased awareness of the need to train Specialised Social Services providers and provision of guidelines in order to perform such training;
- Integration of RDs into social policies and services across MS.

This Work Package has close links with the Work Package 4 of the EJA, dedicated to National Plans for Rare Diseases. In the context of the 25 EUROPLAN conferences scheduled during 2012-2015, there will be an effort to update the indicators on the theme of Specialised Social Services and social policies which are part of the outline of the conference programmes. These will incentivise discussions around the subject, preferably involving the national, regional and local competent authorities in the discussions.

Furthermore, as National Plans and Strategies for RDs are being drafted, reviewed and approved, there is a higher chance of advocating for the inclusion of social policies and Specialised Social Services into the National Plan. This Work Package will work in close collaboration with WP4 to try to secure and guarantee that social policies and Specialised Social Services are not only mentioned in the National Plan but are also assigned a corresponding budget, allowing the development and sustainability of the proposed measures.

APPENDIX III: EJA WP6 WORKSHOP ON GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES – 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

Networking dinner

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

APPENDIX IV: EJA WP6 WORKSHOP ON GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES – LIST OF PARTICIPANTS

Name	Authority/Institution Represented	Country
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 Foundation 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 Federation	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 Hercul	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

APPENDIX V: EJA WP6 WORKSHOP ON GUIDING PRINCIPLES FOR SPECIALISED SOCIAL SERVICES – REPORT

A full report of the workshop on ‘Guiding Principles for Specialised Social Services’ organised within the work package 6 of EUCERD Joint Action ‘Working for Rare Diseases’, on the 6-7th December 2012 can be consulted [here](#).

APPENDIX VI: SPECIALISED SOCIAL SERVICES – DEFINITIONS

Therapeutic Recreation Programmes

Any organised recreation activity (from a summer camp to an *ad hoc* trip) giving people living with rare diseases the possibility to take a break from thinking about diseases and treatments and focus on fun and leisure.

Respite Care Services

Short term care for people living with rare diseases so that family members and carers can experience temporary relief from the stress of care-giving, while making it possible for people living with rare diseases to follow their usual daily routine.

Adapted Housing

Group homes aiming to help people living with rare diseases to enjoy the highest possible level of autonomy, in their own home, where they are supported by specialised staff.

Resource Centres

A combination of information provision and social and medical services, often under partnership or in cooperation with Centres of Expertise. These centres are specialised in handling rare complex cases and provide services such as training courses, information and guidance, information about social services, documentation and research, daily support therapies, medical and psychological consultations.

APPENDIX VII: BIBLIOGRAPHIC REFERENCES

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