



EURORDIS

FOCUS ON SOCIAL SERVICES

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EURORDIS specific actions:

- } Eurordis has supported all key points in the Commission Communication and the Member State Recommendations
- } Already taken action, in particular on the following issues
 - Orphan medicinal products
 - Specialised centres and reference networks
 - Research on rare diseases
 - Registries and databases
 - Empowerment of patient organisations...

Social services: advocacy

→ With the Rhapsody project Eurordis has begun looking at the crucial issue of social services, essential for coping with disease on a daily basis.

} Already achieved

- Specific mention of ‘specialised social services: help lines, respite care services and therapeutic recreation programmes’ in the Commission Communication on Rare Diseases
- November 2008

Council Recommendation on action in the field of rare diseases



EURORDIS
Rare Diseases Europe

- Gathering and pooling national expertise to support:
 - (a) the sharing of best practices on diagnostic tools and medical care as well as
 - education and social care in the field of rare diseases;

- Empowerment of Patient organisations:
 - Promote the activities performed by patient organisations, such as awareness-raising,
 - capacity-building and training, exchange of information and best practices, networking and
 - outreach to very isolated patients.



Rapsody outcomes

□ www.rapsodyonline.eu



Help Lines



A European network

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- A network to improve the quality of services.
- The more advanced services sharing their expertise with the start ups.
- Reflect the very diverse range of services that exist
- Rigorous membership criteria to ensure high standards.
- ‘Convergence plan’, training sessions and on site visits to help with reaching criteria.



Communication and promotion

- Caller profile analysis.
 - } Activity statistics for whole help line network
 - } Imperative that all use the orphacode for listing diseases for this to be a success.
 - } Already completed a test period with six help lines

- Direct link from www.eurordis.org to help line listing on rapsodyonline.eu



Technical tools

- Online call recording software for any help line that would like to use it.
- The answers will be anonymised and part of a central database. They will be shared and searchable by 'keywords' in English and in local language.
- Platform for **isolated patient databases** to compare lists and find matches.
- The tools can be translated into new languages on demand.
- Standardised self evaluation forms

Technical tools 2

- EU wide common 116 number for harmonised social services e.g 'Missing Children number'
 - } Application currently being prepared
 - } Commitment of five services in five different member states needed



Respite Care Services



Respite Care Services

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- Respite care costs versus long term residential care costs
- Rapsodyonline.eu: listing of existing services
- Webpage for each service, including:
Availability, location, Diseases catered for, Medical services, Availability, etc.,
- Exchange of best practices (learning from the nordic model)
The online information can serve as a roadmap for any association/ establishment that would like to set up a respite service.



Therapeutic Recreation Programmes





Therapeutic Recreation Progs

- 50 existing therapeutic recreation programmes identified amongst rare disease community so far (identification and directory never done before)
- All invited to update their information on the rapsodyonline listing. Including:
 - } activities
 - } diseases that can be managed
 - } qualifications of staff, etc.

Hendaye example: Neuro Muscular Diseases (MNM)

Spinal muscular atrophy types 2 & 3
Congenital muscular dystrophies





Integration at School



Integration at school

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- Working group including Agrenska and Integrascoll
- Identification of similar initiatives across Europe and then translation of materials.
- Upload to www.rapsodyonline.eu

How to get involved

- Currently in contact with 50 European help line services
- Timeline: membership applications to help line network from September 2009.
- Contact Shane Lynam to add your Respite Care Service or Therapeutic Recreation Programme to the listing.
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