

DIS-QOL PROJECT

Quality of Care and Quality of Life for People with Intellectual and Physical Disabilities:
Integrated Living, Social Inclusion and Service User Participation

Newsletter from the Barcelona center

Summer 2006

Dr. Ramona Lucas & Dr. Sara Doménech

It's summer and before going on vacation we want to share with you our DIS-QOL activities during the first year.

Also, we want to appreciate the local centers their collaboration in the Project.

Overview of the project

The DIS-QOL is an 3-year Project funded by the European Commission with 12 centers participating: Edinburgh, UK (Coordinator); WHO, Geneva; Barcelona, Spain; Paris, France; Prague, Czech Republic; Tromsø, Norway; Guangzhou, China; Izmir, Turkey; Vilnius, Lithuania; Sicily, Italy; Hamburg, Germany, Tilburg, Netherlands. Also, collaborate in the Project: Porto Alegre, Brazil; Montevideo, Uruguay; Bangalore, India and Auckland, New Zealand.

The **aim of the DIS-QOL Project** is to assess the impact of different models of care for people with disabilities, and the contribution of care model to **quality of care** and **quality of life**.

Also, the study will examine whether the policy initiatives on social inclusion and user participation have had any impact on **attitudes to disability**, perceived stigma and the experience of discrimination in different cultures and whether there are common features that generalise across cultures.

The Project comprises 9 Workpackages (WP): WP1. Review of Literature; WP2. Preparation of Taxonomy of Care and establishment of QOL determinants; WP3. Focus Groups; WP4. Development of Pilot Modules; WP5. Pilot Data Collection; WP6. Pilot Data Analyses; WP7. Development of Field Trial Modules; WP8. Field Trial of Measures; WP9. Dissemination/Implementation

WP1. The objective was to review the current national and international literature relating to physical and intellectual disabilities in participating centers in order to identify key determinants of quality of care, the impact of the fit between individual needs and current care options, and the contribution of quality of care and support to the quality of life of people with disabilities.

WP2. The objective was to prepare a taxonomy of typical care provision (relating to both intellectual and physical disabilities) at national, regional, and individual level.

WP3. The objective was to run focus groups with individuals with physical or intellectual disabilities and their carers to address issues relating to need, current care options, attitudes and subjective experiences, and quality of life in each of the participating centers. Also, to determine the relevance of existing measures of disability (e.g. the WHODAS-II) and quality of life (e.g. the WHOQOL-ID, WHOQOL-BREF) in relation to the current target population in order to identify gaps and areas in need of expansion/modification.

What we have done?

We have been involved in the Project since it began in July 2005.



Instituto Catalán Envejecimiento.
Catalan Institute on Aging.
Barcelona.

WP1. We performed the review of the current national literature relating to intellectual and physical disabilities in relation to Quality of Care, Quality of Life and Attitudes towards disability.

Main findings:

Spanish society does not considered people with disabilities as a main social problem.

The Quality of Life Questionnaire (QOL-Q) is used to evaluate the quality of live of persons with disabilities.

Specific QOL measures used for people with physical disabilities are the Parkinson's disease quality of life questionnaire (PDQ-39) and the Functional Assessment of Multiple Sclerosis (FAMS).

In summary, in Spain there is not much information on QOL, QC and Attitudes among people with any type of disability.

WP2. We prepared a taxonomy of typical care provision at national (Spain) and regional (Catalonia) level, for intellectual and physical disabilities.

Main findings:

Most of the resources available are for two both types of disabilities, intellectual and physical.

These are: Primary Health Care Services, Home Help Services, Day Services, Residential Centres and Specialized Centres.

For both Physical and Intellectual Disabilities there are economical and technical aids available.

Nevertheless, the Quality of Care in our country is insufficient to cover the needs of the people with disabilities.

WP3. We have run ten focus groups (FG) with patients, families and professionals of people with Down Syndrome, Parkinson's Disease and Multiple Sclerosis.

We plan to run FG in Dementia.

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We hope to update all of you our DISQOL activities soon!

If you want to join us in this newsletter, please, contact us:

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Ethical permission to run focus groups was obtained from the CEEAH (Comité Ética Experimentación Animal y Humana) (UAB).

Groups discussions were divided into three parts.

First, participants discussed the concept of quality of care (QOC), what contributed most to the QOC of such individuals.

Secondly, what factors were important to the quality of life (QOL).

Thirdly, the prevailing Attitudes to Disabilities in the local culture were discussed. All FG were audio-taped .

DIS-QOL Meetings

- August 2005. First DIS-QOL meeting. Edinburgh, U.K.
- June 8th. Second DIS-QOL meeting. Caltanisseta, Italy.



Second DISQOL meeting.
Caltanisseta, Italy

Conferences, courses

- February 10th.
Conference.
Barcelona.
- July 11th.
Conference. Summer course.
University of Lleida.



Steering Group

Local collaborating centers

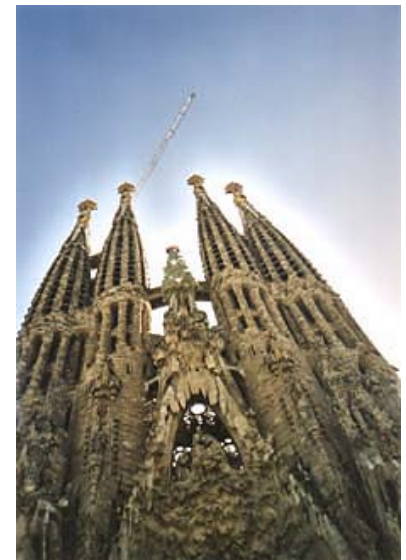
- 1) *Fundació Catalana Síndrome de Down.*
(<http://www.fcsd.org/eng/index.htm>)
- 2) *Hospital de Dia de Barcelona.*
Fundació Esclerosi Múltiple
(<http://www.fem.es>)
- 3) *Unitat de Parkinson. Hospital de Sant Pau.*
- 4) *Associació Alzheimer Catalunya*
(<http://www.alzheimercatalunya.org>)



Fundació Esclerosi Múltiple.
Professionals

Next activities

- October 13th.
INTERNATIONAL SOCIETY
FOR QUALITY OF LIVE
RESEARCH. 13TH ANNUAL
CONFERENCE. ISOQOL.
Lisbon.
Conference. Workshop.
www.isoqol.org



Sagrada Família. Barcelona.



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