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Project Acronym: DIS-QOL

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

Instrument: Specific Targeted Research Project (STREP)

Thematic Priority: Priority 8: Scientific Support to Policies

Action Line: Policies 2.4: Quality of Life Issues Relating to People with Disabilities

DIS-QOL PROJECT
EXECUTIVE SUMMARY
FINAL ACTIVITY REPORT
2005 - 2008

Name of Project Co-ordinator: Professor Mick Power
Coordinator Organisation: University of Edinburgh, UK

Project Start Date: 01 July 2005 **Duration:** 42 months
Period of Report: 01 July 2007 - 31 December 2008 **Date of Preparation:** 25 February 2009
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EXECUTIVE SUMMARY

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*

Project Summary

The project was designed to investigate the quality of care and quality of life of people with disabilities in relation to developments in social policy and typical examples of service practice, and focused on the subjective experience of individuals with disabilities within these frameworks.

The project aims were to investigate the extent to which typical care and support options promote integrated living, social inclusion and service user participation; the role of attitudes to disability and persons with disabilities in relation to the delivery of care and service users' experience of social justice; and the impact of different service models and care practices on the quality of life of individuals with disabilities.

The project objectives were to:

- Develop three cross cultural measures for use with people with intellectual and physical disabilities: a measure of quality of care (the Quality of Care & Support or *QOCS*); a measure of the quality of life of disabled persons based on the existing World Health Organisation's quality of life measure, the *WHOQOL-BREF*, but adapted and extended for use with disabled persons and their carers (*WHOQOL-DIS*); a measure of attitudes to disability and to persons with disabilities (the Attitudes to Disabilities Scale or *ADS*)
- Carry out a large cross cultural study of the quality of care and quality of life of people with disabilities, and attitudes to disabilities and to persons with disabilities, within both European and non-European participating centres.
- Draw conclusions and inform social policy and practice in relation to intellectual and physical disability in the European Union, and more globally.

Project Consortium

The study formed part of a large cross-cultural project involving a partnership between eighteen different research centres in Europe, Asia, South America and Australasia, including Edinburgh, UK; WHO, Geneva; Barcelona, Spain; Paris, France; Prague, Czech Republic; Tromsø, Norway; Izmir, Turkey; Vilnius, Lithuania; Sicily, Italy; Hamburg, Germany; Tilburg, The Netherlands; Guangzhou, China; Porto Alegre, Brazil; Bangalore, India; Montevideo, Uruguay; Auckland, New Zealand; Melbourne, Australia; Budapest, Hungary. The international project was led by the University of Edinburgh and within the research consortium, each centre carried out the same essential project components simultaneously and collaboratively, under the overall coordination of the Edinburgh centre.

Project Management, Coordination and Review

The project group held four full scientific meetings (August 2005, June 2006, June 2007 and September 2008); and two smaller working group meetings (November 2006 and December 2007) to develop, monitor, and review the programme of work. In addition, the Project Steering Group held three meetings (June 2006, June 2007 and September 2008) to maintain an oversight of progress and provide international expertise.

A formal Mid-Term Review of the project was undertaken in June 2007. The project was rated satisfactory, as addressing important objectives that remain relevant, and having achieved most of its objectives and technical goals for the project stage. In addition, the consortium was noted as working effectively and the project was reported to be well managed.

Project Schedule

The original project schedule involved the work being carried out over 36 months from July 2005 to June 2008. However, as a result of slippage in the workpackage timetable, regular revisions were made to the project schedule and a formal review of the status of the project was undertaken in December 2007. As a result of this, a six-month cost neutral extension to the project was sought in March 2008 and granted in May 2008. Thus the final duration of the project was 42 months.

Work Performed

The project comprised nine workpackages: an international literature review and 13 separate national literature reviews were carried out (WP 1); national taxonomies of care were prepared for 13 countries (WP 2); 78 focus groups were conducted in 14 national settings with diverse cultural profiles (WP 3); the pilot modules of the three new measures were developed through collaboration in 18 research centres (WP 4); pilot data was collected on 1400 participants (491 people with intellectual disabilities and 909 people with physical disabilities) in 15 research centres (WP 5); pilot data analysis was undertaken by the coordinating centre and reviewed by representatives of 7 centres (WP 6); the field trial modules of the measures were developed through collaboration in 16 research centres (WP 7); a field trial study was conducted in 14 centres worldwide (WP 8) and data were collected on 3772 participants (1158 people with intellectual disabilities and 2614 people with physical disabilities); as part of a subsidiary cross cultural proxy study data were collected on 876 participants responding on behalf of people with intellectual disabilities (228 relatives of people with intellectual disabilities and 648 care staff); analysis of the global data relating to the performance of the measures (psychometric properties) and the outcomes of the cross-cultural and proxy studies was undertaken by the coordinating centre (WP 8); and finally, dissemination of results and project outcomes (WP 9) was undertaken (and will be continued into 2009 and 2010).

Ethical Issues

The Project Ethics Committee (PEC) met formally on two occasions during the life of the project, in June 2007 and September 2008; and a Project Ethics Officer was appointed in June 2007 to coordinate and monitor ethical aspects of the project on behalf of the project group.

Apart from delays experienced by some centres in obtaining ethical approval for the work, no major ethical issues or problems arose during the project. However, given the importance of the documentation relating to the ethical conduct of the project (e.g. records of Ethical Approval, Information Sheets, Consent Forms, Pilot and Field Trial versions of the measures translated into the range of languages covered by the project) the PEC agreed that the Project Officer should collect and collate a set of relevant materials from all centres on behalf of the consortium.

Project Results

Three cross cultural measures were developed within the project and subsequently tested within the eighteen participating and contributing centres, each measure having related versions for physical disability (D) and intellectual disability (ID):

- A measure of quality of care and support (QOCS-D and QOCS-ID)
- A measure of the quality of life of disabled persons based on the existing World Health Organisation's quality of life measure, the WHOQOL-BREF, but adapted and extended for use with people with disabilities (WHOQOL-DIS)
- A measure of attitudes to disability and to persons with disabilities (the Attitudes to Disabilities Scale) with parallel versions relating to general attitudes to disabilities (ADS-D (G) and ADS-ID (G)) and to attitudes to personal disabilities (ADS-D (P) and ADS-ID (P))
- The ADS-D (G) is suitable for use with the general population also

In addition, proxy versions of two of the measures were developed for use in connection with people with severe intellectual disabilities lacking the capacity to respond directly by self report, providing a means by which family members or care providers may respond indirectly as proxies:

- A proxy measure of quality of care and support (QOCS-ID (Proxy))
- A proxy measure of quality of life (WHOQOL-BREF and WHOQOL-DIS (Proxy))

Cross cultural comparisons of quality of care, quality of life and attitudes to disability are being conducted with reference to both geographical location and culture; and the impact of relevant socio-demographic information such as gender, age, and health and disability status is being examined.

Project Outcome & Impact

The project has been successful in meeting its aims and in some respects has surpassed its objectives, for example in relation to the range of the measures developed; and the breadth and richness of the data obtained, and the range of potential analyses to be undertaken, has provided the opportunity for the work to continue beyond the scope of its funding.

It is anticipated that the project will have significant impact due to the psychometric advantages of cross-culturally designed measures; the utility of the proxy versions of the measures; the usefulness of the set of measures in research, epidemiology and as clinical tools; and the utility of the instruments as outcome measures for:

- The evaluation of service provision and the outcomes of different approaches to health and social welfare for people with disabilities both within and between cultures (with less risk of cultural bias).
- Establishing baselines, devising programmes to enhance the lives of people with physical and intellectual disabilities, and evaluating the outcomes of systematic interventions, in the context of individual goals, expectations, standards and concerns.
- Identifying the impact of policies on quality of care and quality of life for people with intellectual or physical disabilities, and clarifying which areas of resource investment provide the greatest level of gain.

Dissemination of Knowledge

Dissemination of knowledge from the project was carried out in parallel with the progress and completion of the workpackages, with a number of investigators presenting papers at national and international conferences and seminars. A plan for the dissemination of knowledge was developed and thirteen working / writing groups were convened to draft the initial set of publications from the project.

In addition, the possibility of a high level international policy conference aimed at policy makers, service developers, service users, researchers and practitioners (in collaboration with the EC and WHO) is under consideration; and many of the participating centres will use local (non-EC) resources to continue the work of project dissemination well beyond the official project end.