

EXECUTIVE SUMMARY

This report outlines the first year's progress of a European Commission funded project, *POMONA Health Indicators for People with Intellectual Disabilities: Using an Indicator Set*. The project duration is three years from May 2006 to April 2008.

The project provides a unique opportunity to develop and test a set of health indicators specific to people with intellectual disabilities (also termed learning disabilities in the United Kingdom and mental retardation in the United States). These health indicators will be tested through the production and implementation of a health interview survey, conducted with people with intellectual disabilities and/or nominated advocates, in fourteen European countries.

The project comprises nine work packages in total, the first five of which fall within the duration of this first interim report. Two work packages, 'Coordination' and 'Dissemination' extend the full three-year duration of the project. Coordination activities are documented throughout the minutes of project meetings, four of which have been held to date hosted by partners in Italy, Spain, Austria and Slovenia. The meetings provide a useful framework to appraise progress and plan for future activities. Dissemination activities to date total thirty-five completed activities, including peer-reviewed publications, presentations at international conferences, and meetings with competent authorities. A further ten activities are scheduled for the second year of the project.

The third work package comprised an essential task in the project – the operationalisation of a previously developed set of health indicators (POMONA I project 2002-2004) into a survey protocol that could be administered to people with intellectual disabilities and / or nominated advocates across fourteen European countries. The survey protocol has now been developed, translated and validated for use in each country. The process of obtaining research ethics, a vital step in light of the vulnerability of this population, is almost complete in participating countries. Ethical approval will permit the collection of pilot data, a key task of work package five.

Project partners, as scheduled in work package 4, have now each completed a report detailing the status of people with intellectual disabilities and the availability of health, residential and education services in participating countries. The reports provide a useful context from which survey samples can be drawn and from which survey results can be interpreted.

The second year of the project is largely concerned with the substantive task of data collection in each participating country. This data will provide a unique standardised insight into the health status of a sample of adults with intellectual disability and detail their access to health care services throughout Europe. Year three provides an opportunity to analyse this data in depth and to identify health disparities between those with intellectual disabilities and their age-related peers within the general population. The final year of the project also provides an opportunity to examine the issue of disability training and awareness for health care professionals who work with this population.

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TABLE OF CONTENTS

Acknowledgements	I
Project Partners & Researchers.....	II
Executive Summary	IV
1. Background.....	1
1.1 The Health Monitoring Programme	1
2. POMONA I.....	2
2.1 People with Intellectual Disabilities in European Health Monitoring.....	2
2.2 People with Intellectual Disabilities: Defining the Population	2
2.3 People with Intellectual Disabilities: Health Disparities	3
2.4 The Need for Health Monitoring.....	4
2.5. POMONA: Health Indicators for People with Intellectual Disabilities in the Member States	5
3. POMONA II	10
3.1 POMONA II Objectives	10
3.2 POMONA II PROGRESS TO DATE	11
3.3 POMONA II PROGRESS TO DATE – WP1 Coordination.....	12
3.3.1 All Partner Meeting, Rome, Italy	12
3.3.2 1 st Regional Meeting, Barcelona, Spain	12
3.3.3 2 nd Regional Meeting, Graz, Austria	13
3.3.4 3 rd Regional Meeting, Ljubljana, Slovenia.....	13
3.3.5 Coordination of Project Activities 2005-2006.....	14
3.4 POMONA II PROGRESS TO DATE – WP2 Dissemination.....	15
3.5 POMONA II PROGRESS TO DATE – WP3 Operationalising the Set of Indicators	23
3.5.1 Operationalisation of the Indicators & Development of the Survey Protocol.....	23
3.5.2 Translation & Validation of the Survey Protocol.....	27

3.6 POMONA II PROGRESS TO DATE – WP4 Report on Systems in Participating Member States.....	29
3.7 POMONA II PROGRESS TO DATE – WP5 Pilot Survey	32
3.8 POMONA II PROGRESS TO DATE – WP6 Draw Survey Samples in each Participating Member State.....	36
3.9 POMONA II PROGRESS TO DATE – WP7 Data Collecting in Participating Member States.....	37
3.10 POMONA II PROGRESS TO DATE – WP8 Analysis of Data.....	38
3.11 POMONA II PROGRESS TO DATE – WP9 Training of Health Professionals.....	39
4. POMONA II Future Work.....	41
ANNEX I POMONA I Partners.....	42
ANNEX II Health Interview Surveys Conducted in Partner Countries in Europe	43
ANNEX III All Partner Meeting, Rome.....	58
ANNEX IV 1 st Regional Partner Meeting, Barcelona	65
ANNEX V 2 nd Regional Partner Meeting, Graz.....	70
ANNEX VI 3 rd Regional Partner Meeting, Ljubljana.....	75
ANNEX VII POMONA Survey & Covers in European Languages	81
Belgian Cover	102
Dutch Cover.....	103
Finnish Cover.....	104
French Cover.....	105
German Cover.....	106
Italian Cover	107
Lithuanian Cover	108
Norwegian Cover.....	109
Romanian Cover	110
Russian Cover.....	111
Slovakian Cover	112

Spanish Cover	113
ANNEX VIII Member State Reports:	114
Austrian Report	114
Belgium Report	138
Finland Report	149
France Report.....	166
Germany Report	202
Ireland Report	214
Italy Report.....	230
The Netherlands Report.....	239
Norway Report.....	250
Romania Report	265
Slovenia Report	282
Spain Report	294
United Kingdom.....	309
Lithuania Report	325
ANNEX IX Pilot Study Protocol.....	326