

ANNEX VI: 3rd REGIONAL PARTNER MEETING, LJUBLJANA

3rd Regional Meeting – 1-4 December 2005

**Institute of Public Health of the Republic of Slovenia
Ljubljana, Slovenia**

Friday 2 December 2005

9.30am – 12.30am

11am – Coffee Break

- 1 Review of the 1st & 2nd Regional Meetings in Barcelona & Graz
- 2 Housekeeping
Detailed budgets, travel claims, partners claim travel and subsistence from UCD
- 3 WP 3 – Review of Questionnaire – open & closed items, scales, back translation

12.30 – 14.00 Lunch Break

14.00- 17.00

- 4 Opportunity to meet colleagues from Ljubljana – presentations regarding the status of people with intellectual disability in Slovenia & Pomona
- 5 WP 5 – Progress on Pilot Study – Consent, Ethics & Data Protection.

Saturday 3rd December 2005

9.30am – 12.30am

11am – Coffee Break

- 6 Continuation from Friday's agenda
- 7 WP 4 – Member State Reports – templates
- 8 Opportunities for dissemination/awareness of Pomona
- 9 Any other business

Attendees

- (1) Dr Dasa Moravec Berger, Laura Sustersic Zorn, Blanka Colneric, Tjasa Pecnik, Slovenia
- (2) Dr Alexandra Carmen Cara, Romania
- (3) Dr Fino Buono & Martina Musumeci, Sicily
- (4) Prof Geert Van Hove, Belgium
- (5) Christine Linehan, Ireland – Chair of Meeting

1 Review of the 1st & 2nd Regional Meetings in Barcelona & Graz

Christine Linehan briefly reviewed the conclusions from partner meetings at Barcelona and Graz.

2 Housekeeping; Detailed budgets, travel claims, partners claim travel and subsistence from UCD

Partners were reminded that an invoice to claim travel & subsistence for the Ljubljana meeting would be sent from UCD following the meeting. Partners will need evidence of travel (e.g. receipts, boarding card, ticket, etc) to attach to the invoice. The invoice should be sent to Marie O Connor, Senior Administrator, UCD Centre for Disability Studies, D003 Newman Building, University College Dublin, Belfield, Dublin 4.

Partners were also reminded to keep copies of all documentation sent to UCD. The European Commission will conduct an audit of the project at its conclusion and documentation – timesheets, payslips, travel expenses – will be sought.

3 WP 3 – Review of Questionnaire – open & closed items, scales, back translation

A third draft of the questionnaire was presented to partners based on the feedback from the regional meeting of partners at Graz, Austria.

The following items were discussed:

(1) The use of items taken from generic health surveys:

Partners agreed that the use of items from general population health surveys would allow comparisons between the health of people with intellectual disability and the general population. Also, the use of items from general population health surveys would reflect the aims of the European Commission Health Monitoring Programme that promotes the harmonisation of health surveys across Europe. This may assist in providing sustainability to the work of Pomona. Partners concluded that where possible, Pomona II should attempt to support this harmonisation process.

(2) The use of standardised disability specific scales:

Partners recommended the use of the short ABS form, the PAS ADD and the Aberrant Behaviour Checklist as suggested in the Graz meetings as these are considered highly robust measures within the disability field.

(3) Can we use copyrighted material?

There are copyright issues with these scales:

- i. PAS ADD
- ii. Adaptive Behaviour Scale (Residential)
- iii. Aberrant Behaviour Checklist

Christine explained that she had contacted Pavilion Publishers regarding the use of the PAS ADD, a measure of psychiatric morbidity among people with intellectual disability. The publishers were unable to provide a response at that time, but will respond in due course.

Patricia will be meeting representatives of the American Association of Mental Retardation (AAMR) who publish the Adaptive Behaviour Scale during December 2005 and will ask advice on how we might collaborate.

Aberrant Behaviour Checklist – available at a fee from
<http://www.slosson.com/index2.ivnu>

Some partners, particularly those attached to a university, may have a licence for some of these checklists to be used for research purposes. This would reduce a cost if they have to be purchased. Partners will be asked if they hold licenses for these instruments.

One partner suggested that the World Health Organisation have some scales that might be of interest as the WHO allow researchers to use their questionnaires without payment provided the research is non-profit.

(4) Who responds to the survey?

Different options were explored. A person with severe and/or profound level of intellectual disability is unlikely to be able to answer the survey and is likely to need someone to answer on his/her behalf. A person with mild or moderate intellectual disability will be able to answer some items, but probably not all. Therefore another person will have to assist the person with intellectual disability. There will therefore be different respondents for different interviews. In most cases the person with intellectual disability will require the help of another person (e.g. a family member, a doctor, a paid carer, an advocate, etc.) to answer some of or all of the survey on his/her behalf.

(5) How are we defining our population?

Partners agreed that it would be difficult to recruit people with mild intellectual disability to participate in the survey if they were not receiving a service. In Ireland, this population is called the ‘hidden’ population of people with intellectual disability. In Romania this population often reside in rural areas. Partners suggested that they provide some information on this group of people with intellectual disability in the Member State Reports that begin in January 2006.

(6) The question of IQ.

Draft II of the survey contained an item asking if the individual had undergone an IQ test and if so, to specify the result. This item was removed from Draft III on the basis of discussion at Graz. The inclusion of IQ was discussed again at Ljubljana. Partners commented that Adaptive Behaviour was being measured and that some acknowledgement of whether respondents to the survey had undergone an IQ test should be measured. Partners suggested that the item should be limited to asking ‘Have you ever had an IQ test?’ The result of the test would not be examined. An alternative suggestion was that the question would be phrased ‘Have you ever had a cognitive assessment of intellectual ability?’

Partners noted that different levels of information are provided to people with intellectual disability. In some Member States, individuals are told their exact IQ, while in other Member States (e.g. Italy) individuals are told their level of IQ (e.g. mild, moderate, severe, profound).

(7) Contact with Health Professionals

Partners suggested that ‘therapies’ be included in this list such as physiotherapy, occupational therapy, speech therapy, etc.

(8) Ethic Status

Partners questioned the relevance of this item and suggested that the categories were not representative for many Member States. If the question is retained a suggestion was that it would be coded ‘ethic majority’ or ‘ethnic minority’

4 Opportunity to meet colleagues from Ljubljana – presentations regarding the status of people with intellectual disability in Slovenia & Pomona

Presentations on the health and legal status of people with intellectual disability in Slovenia were made by invited guests:

Dr. Nika Tevz-Cizej, Physician, the Draga Centre, Slovenia
 Dr. Tomaz Jereb, Parent Representative, Sozitie, Slovenia

Copies of these Powerpoint presentations will be put on the Pomona website once permission has been obtained from the speakers.

Both presenters engaged in a Questions and Answers discussion with the partners following their presentation. This provided a unique and valuable opportunity for partners to explore the situation for people with intellectual disability in Slovenia. We are most grateful to the speakers and to Dasa for organising this opportunity.

5 WP 5 – Progress on Pilot Study – Consent, Ethics & Data Protection.

Mike Kerr and Jon Perry (Wales) are currently working on a document that partners can translate and present to an Ethics Committee in each Member State. This document will comprise two parts:

- (1) a protocol outlining the project, the methodology, etc
- (2) the survey

Christine emphasised that every Member State will require ethical approval for the collection of data. Each partner is responsible for the decision of which organisational body can provide this ethical approval. It is imperative that written ethical approval on behalf of each Member State is obtained prior to data collection and is presented in the appendix of the final report for this project.

In addition, partners will take responsibility for obtaining consent (written) from or on behalf of each participant in the survey. As methods differ markedly in each Member State partners will have to examine structures within their own Member State to guide them in this process. It may be necessary to have two consent forms, one on behalf of the individual with the intellectual disability, one on behalf of a third party (e.g. family member, carer, etc).

In order to ensure anonymity partners will have to retain their consent forms – they should not be sent to another Member State with the data.

Christine also emphasised that this survey is a Health Interview Survey (collecting written information on health) and is not a Health Examination Survey (collecting data by examination such as examining a person’s teeth, weighing a person, measuring a person’s height, undertaking a test of vision etc.) This is an important distinction; as under no circumstances should a Research Assistant with the Pomona project engage in conducting a health examination. This distinction will be emphasised in the research protocol presented to Ethics Committees.

All partners will be asked to contact their local Data Protection Commission to ensure that the demographics used in the survey – gender, year of birth and region – are considered anonymised data and can be sent to another Member State for analysis.

Partners suggested that a video conference or conference call might be scheduled after the pilot study.

6 Continuation from Friday’s agenda

(9) Statement on population

Following the discussion above in Section 3 (5: How are we defining our population?) partners suggested that a statement is needed to define the population of people with Intellectual Disability. This is especially important for our colleagues in the European Commission. Partners acknowledge that while between 1-3% of the population are estimated to have an intellectual disability on the basis of IQ being less than 70, only some of these individuals present to services. Geert Van Hove suggested that previous research has defined those with intellectual disability as people who have at some point in their lives used services for people with intellectual disability or professionals who know them well identify them as having intellectual disability¹

(10) What is the methodology of data collection?

Partners suggested that the survey could be posted to the person with intellectual disability or a third party (e.g. family member/carer etc.) in advance of a face-to-face meeting. This would simplify the collection of archival data. Also, another person on behalf of the individual with intellectual disability might best complete Aberrant Behaviour Checklist and PAS ADD etc., as they require the opinion of a third party. Partners suggested that the questionnaire could be colour coded – one colour denoting questions that are best answered by the person with intellectual disability and one colour denoting questions that are best answered by a third party on behalf of the person with intellectual disability. If this suggestion is adopted, the person with intellectual disability will need to be informed that another person is providing responses on their behalf and this will need to be explicitly stated on the consent form.

(11) List of medications

A suggestion at the meeting in Graz was made regarding medication. The suggestion was that medication for epilepsy be asked during the section on epilepsy and that the medication of anti-psychotics be put in the section on mental health. A third list of medications was introduced in the section on common morbidities. Partners at Ljubljana suggested that difficulties would arise with these lists as medications differ in each Member State. One question, where the respondent is asked to list all medications taken by the person with intellectual disability was recommended. Also, partners suggested that the questionnaire should code whether this information was given verbally or whether the respondent actually saw the medication.

(12) Sample size

Partners agreed with the recommendation from the minutes of the meeting in Rome that approximately 60 individuals with intellectual disability should participate from each Member State.

(13) Data entry

Partners in each Member State are responsible for data entry of their surveys either via SPSS or Excel. A codebook will be sent to partners advising how items are to be coded.

¹ Mercer, J.R. (1973). Labelling the mentally retarded: clinical and social systems perspectives. Berkeley: University of California Press

(14) Translation

The process of translation followed by back translation as proposed in the article by Guillemain circulated by Henny was recommended pending cost. Partners agreed that translation costs would be an issue and recommended that if possible university students might be able to provide this service.

(15) Validation of findings

Data from a sub-sample (partners suggested between 5%-10%) should be collected twice by different sources for validation of the material. Partners suggested that pilot data might be useful here. This validation will need to be mentioned on the consent form.

7 WP 4 – Member State Reports – templates

Christine will send a template to partners in the New Year outlining the information required for these reports. It was noted that these reports will have to be extremely brief – Pomona could spend three years writing these reports alone, however these are only one small aspect of the project.

8 Opportunities for dissemination/awareness of Pomona

IASSID 2006 is an opportunity to disseminate information and host an all partner meeting. Partners agreed that they would like the meeting to occur during the conference, not before or after. Partners will be accommodated if they have to leave for presentations. The number of symposia was discussed and partners felt that one was sufficient with approximately four papers. Partners asked that, irrespective of who presents the papers, all partners be named on at least one paper as this is a valuable opportunity that should be shared by all partners.

Christine suggested that partners should disseminate and publish in their own languages. All partners could send Christine information on these presentations / publications and this information should be on the Pomona website www.pomonaproject.org.

9 Any other business

Dasa Moravec Berger and her colleagues were thanked for their assistance and hospitality in hosting this event.