

ANNEX IV: 1st REGIONAL MEETING



Regional Meeting of Partners - Finland 12-15 October 2006

Hotel Aurora, Helsinki

13 October 2006

Present:

Tuomo Määttä, *Pomona* partner from Finland
Matti Iivanainen, Finland
Markus Kaski, Finland
Daša Moravec-Berger, *Pomona* partner from Slovenia
Christine Linehan, Ireland, *Pomona* project manager
Patricia Noonan Walsh, *Pomona* partner from Ireland and project coordinator

9:00 Welcome and introductions to experts from Finland

Short presentation to review progress in completing work packages of Pomona-2
Review of pilot study – powerpoint presentation at Maastricht conference August

10:15 Coffee

10:45 Discussion about *Pomona* survey instrument and pilot study

- 1 We should state clearly in the instructions who should respond to the questions.
 - a. Note: – two standard measures are completed by another informant
 - b. Daša reported about the experience of completing the pilot study in Slovenia among 8 persons with intellectual disabilities. In some cases informants did not know the information required.

- 2 Reliability in the pilot study is to be achieved by conducting a second interview – with a different informant focused on 2 individuals in each group of 8.

How do we resolve discrepancies between informants, particularly when the person with ID may respond differently to family member or staff member?

In some countries, all participants will be interviewed with another person present: this format has advantages. It was noted that the protocol will be posted to respondents ahead of time so that the standardized measures and administrative elements will be completed by an informant, and the middle section targeted at the individual with intellectual disabilities may be previewed.

- 3 When data are analyzed, we must record as variable whether or not another person attended the interview with a respondent, or whether it was a proxy interview (Page 3, Q A-8: ‘Who is attending the interview’).

One suggestion is that these data about solo respondents could be analyzed separately, and the findings discussed in the report.

- 4 Question O 2: coding from 0-5 must be corrected to make sure data coding is same as questionnaire.
- 5 Medication: can all partners consult same source (WHO – ATC or from anatomy, disease, chemical)? It is crucial for all partners to supply comparable information.

Staff informants are likely to provide trade and generic names.

Christine will consult Mike Kerr at Cardiff University 31 October about this issue.

Original purpose was to inspect results of PAS-ADD and compare with survey findings about prevalence of psychotropic medications.

It is important to know how many and what combinations of drugs some people may take – to consider interactions, for example. It was agreed that experts should be involved in interpreting our findings.

- 6 Section 3: Is there a manual for administering this section (eg, responding to ADL items)?
- 7 Health conditions (I): Respondent can tick on protocol, but how to code these for SPSS?

It was noted that there are challenges in identifying those with autism or autistic spectrum disorder/ or ‘autistic tendencies’.

- 8 G-1: Cause of disability? Could ‘autism’ be included as a cause?
Another cause is likely to be cerebral palsy.

12:30 Lunch

Presentations – Panel of Finnish experts (reference materials^{1 2 3})

13:30 Presentation: *Health Care in Finland* by Dr. Markus Kaski, Rinnekoti Foundation and Rinnekoti Research Foundation (see powerpoints)

13:45 Presentation: *Special competence in intellectual disability medicine in Finland* by Dr. Matti Iivanainen, Rinnekoti Research Centre and University of Helsinki (see powerpoints)

14:00 Presentation: *Health services for persons with intellectual disability* by Dr. Marja-Leena Hassinen, City of Helsinki Health Centre, Department of habilitation for persons with intellectual disability (CD about services available from Dr. Hassinen)

- serves people within, outside institutions
- Helsinki centre provides services for n= 1,700 registered persons
- these centres are within hospitals sector

15:00 Coffee

15:15 Prevalence of ID in Finland: update by Dr. Iivanainen

¹ Ministry of Social Affairs and Health (2004). *Health Care in Finland*. Helsinki: Brochures of the Ministry of Social Affairs and Health, no. 11.

² Koskinen, S., Aromaa, A., Huttunen, J. & Teperi, J. (Eds) (2006). *Health in Finland*. Helsinki: National Public Health Institute KTL, STAKES, Ministry of Social Affairs and Health.

³ Finnish Medical Association (2006). *Physicians*. Helsinki: FMA. Leaflet available from: (www.medassoc.fi)

Previous studies:

- * K. Patja: this study did not identify those with mild level of ID
- * Two other regional studies yielded prevalence of 1.3

The most recent study used 8 benefits registers as source of data, and this yielded a prevalence rate of 1%. The paper has been submitted to JIDR (in press). Some findings were appeared in presentation by Westerinen, H. (2004) at 12th IASSID World Congress at Montpellier. Westerinen H, Kaski M, Virta L, Almqvist F, Iivanainen M. Register based prevalence of intellectual disability. 12th IASSID world congress, 14–19.6.2004 Montpellier. Abstract. J Intellect Disabil Res 2004; 48: 488.

FAMR identifies a population about half of this size based on persons in contact with services (about 28,000 persons).

A survey by Finnish comprehensive schools estimated that about 2.5% of children educated for 11 years in their system.

15:35 Legislation about health and ID in Finland

There are currently two pieces of legislation – one about people with disabilities, and a second about people with ID. Discussion is ongoing: how might these instruments be combined? A dilemma is that there are different funding sources. Main responsibility rests with Municipalities (432).

Disability policy now moves toward stating a programme and targets. Next would be a proposal for legislation making smaller changes because needs of two groups are very diverse.

One law says there should be a special polyclinic in each of 18 ‘special care districts’ targeting the health of people with ID. People with ID also have access to primary and secondary health care, and in addition have special, complementary health care.

Discussion

Legislators would find it helpful to have (1) epidemiological data; and (2) how much health services are needed for people with ID; (3) co-morbidity data; and (4) population-based data. It would be good to know what health outcomes for people with ID are worse than those for the general population.

Indicators are useful also for measuring health in the general population.

16:00 End of meeting

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9:00 Start of meeting and agreement on agenda

9:15 Project administration

Reports

An *Interim Report* was submitted in July and has been accepted by the Commission. It is now posted on the project website.

The *Financial Report* was submitted at the end of July. It seems that it has been approved and if so, then the second tranche of payments to partners will follow shortly. We will confirm whether a second *Interim Report* is due in July 2007, and details of the payment schedule.

European Commission

PNW summarized recent changes in the Commission at the level of Public Health/ Dir on Health Information. The Working Party on Mental Health, where *Pomona* had been represented, was dissolved in February 2006. The project will be represented at the next meeting of the Mortality and Chronic Conditions Task Force (Health Information Strand) that takes place in Luxembourg on 11 December. We sent a brief report to NIVEL, the secretariat for the new Task Force, about our progress, and will also submit a short article for the Nivel *Newsletter*.

Budget

Christine reminded partners about the procedures for claiming travel costs, and asked them to take care in completing legibly for the attention of the accountants who process these claims. Partners are urged to **keep copies of all receipts**. She also reminded partners that they must record timesheets for the work of research

assistants and also partners' own time. It is essential to have this information in the event of financial audit.

Partners receive a budget that covers all project expenses except travel. If partners consult an external expert for up to 5 days, they pay the expert from their own budget on receipt of an invoice. This process should be clarified between partners and the financial officers at their institutions. Christine sent each partner an itemized budget in 2005.

Slovenia - update:

It is likely that the participating institution will remain the same. If there is to be a change, this will take place after 1 January 2007.

10:10 Coffee

10:30 Review of Work Packages

Progress to date:

October 2006 is Month 18 of the project – the half way mark.

- WP 1 – Coordination (months 1-36) (Ireland)
- WP 2 – Dissemination (months 1-36) (Ireland)
- WP 3 – Operationalizing the set of indicators (completed) (the Netherlands)
- WP 4 – Country reports: 13/14 completed - included in *Interim Report* (Ireland)
- WP 5 – Pilot Study – now being concluded (UK)
- WP 6 – Sampling – now underway (the Netherlands and Germany)
- WP 7 - Data gathering
- WP 8 – Data analysis (Finland and Ireland)
- WP 9 – Training of health professionals

WP 2 - Dissemination

We shall submit a short article for inclusion in the NIVEL Newsletter.

We are currently preparing: (1) Brief Report on *Pomona-2* for JPPID; (2) an article reporting on the survey of national HIS/HES surveys by *Pomona-1* partners; (3) a paper about operationalizing the survey protocol by *Pomona-2* partners.

Christine will present a paper about *Pomona-2* at the EUPHA conference in Montreux, Switzerland, in November 2006.

WP 5 – Pilot Study

The survey protocol has been applied in the pilot study (WP 5). Christine will meet Mike Kerr and Jonathan Perry in Cardiff at the end of October to review this work package. Any suggested changes to the protocol may be discussed with the partners at regional meetings in Vilnius and Bucharest in November 2006. It is likely that the final version of the protocol will be available at the end of November 2006.

WP 6 – Sampling:

Meindert Haveman (Germany) and Henny Lantman (the Netherlands) are leading this work package. They have asked all partners to advise them in a brief summary about how they intend to identify participants in each country.

Finland: Tuomo presented the sampling strategy he has prepared, using population-based data for a region that reports 750 individuals with intellectual disabilities, of whom 500 are adults.

Slovenia: Daša reported that she will use two contact points, one for the population living in institutions and a second through a family association for the population living in the community.

Ireland: Christine described the proposed strategy of randomized selection across stratified groups identified through two service provider agencies.

WP 7 – Data gathering

This is likely to begin in December 2006. Anonymized data should be returned to Christine Linehan in Dublin.

Each partner will ultimately receive a file with all anonymized data. However, partners must agree on a strategy for further analysis and publications.

WP 8 – Data analysis

Finland and Ireland will lead this work package, beginning in May 2007.

WP 9 – Training for health professionals

Partners are asked to submit to Henny Lantman any models of good practice in their countries. Also, any key issues that arise at the Regional meetings, or during data gathering, should be documented. The outcome of this WP will probably be in the form of a set of recommendations.

11:15 Any other business:

In Maastricht, it was suggested that a regional meeting could take place May 2007 in Oslo: the IASSID Aging and ID Roundtable takes place in Oslo 20-22 May. Other sites for regional meetings could be suggested in the next few months.

We thanked Tuomo for his excellent hospitality and organization. Special thanks are due to the Rinnekoti Foundation for their support in organizing a very useful meeting in Helsinki. The meeting concluded.