

1st Meeting of Ad Hoc Expert Group on Institutional Care Reform (on Long-Term Care Reform), 10 March 2009

The Ad Hoc Expert Group meeting was attended by the following Members: Jan PFEIFFER (Chair), Carlotta Besozzi (accompanied and later replaced by Ask ANDERSEN from EDF), Ines BULIC, Geert FREYHOFF, Anne-Sophie PARENT, and Luk ZELDERLOO. Josee VAN REMOORTEL represented Mental Health Europe (replacing Mary van Dievel). The European Commission was represented by Jan JAŘAB (Cab Špidla), Silvio GRIECO (secretariat) and Trude ELIASSEN (both DG EMPL), Jorge PINTO ANTUNES (DG SANCO) and Anna ZITO (DG JLS).

Programme

1. Introduction of the group, opening statements by Chair and Members

Members of the Expert Group and Commission representatives (secretariat, observers) introduced themselves. Jan JAŘAB representing Commissioner ŠPIDLA, explained why the Commissioner had wished to create such a group, namely to **link the four existing and distinct "narratives of de-institutionalisation" (with regard to persons with disabilities, children, the elderly and the mentally ill) together, drawing common lessons from them which can be generalised and summarised in the form of recommendations.**

The Chair, Jan PFEIFFER, delivered an opening statement on the phenomenon of large residential institutions, their historic role (of control and containment), and on the **development of policies towards a more person-centred approach which values individual dignity, autonomy and community living.** He emphasized the staff who work in large institutions are often dedicated and well-intentioned people; however, the structures in which they work largely determine their modes of behaviour. Citing an estimate of some 10 million people in residential institutional care (in the EU), he pointed out the urgent need to use available instruments - e.g., EU Structural Funds - as instruments for change, rather than allowing them to support and enlarge the existing institutional frameworks, particularly in new Member States. Statements of other Members followed:

- Anne-Sophie PARENT argued that the key issue was **quality and its control** rather than any particular relationship with size and format of institutions, their settings, or buildings that they use. She mentioned that even small-scale services may replicate the paternalistic culture of large institutions, while buildings previously used by large institutions can undergo a beneficial transformation into inter-generational communities.
- Geert FREYHOFF warned that old models of institutional care should **not be seen as being mainly the problem of Central and Eastern Europe.** While such institutions in Western Europe may provide far better conditions in material terms, this fact may paradoxically result in their better acceptance by the politicians and the public, - yet they, too, tend to isolate the persons rather than include them in the community.
- Carlotta BESOZZI raised the issue of the different legal frameworks in Member States as regards legal capacity. People living in institutions in many countries do not enjoy legal capacity on an equal basis with others, and do not have the right to redress.
- Ines BULIC emphasized the need to perceive the issue **from a human rights perspective,** using the existing human rights framework.

- Josee VAN REMOORTEL confirmed that major investments in refurbishment of large residential institutions, or indeed in building new ones, are under way in a number of Member States, with the **EU Structural Funds being one of the main sources of investment into this build-up.**
- Luk ZELDERLOO spoke about the way in which staff tend to gradually adapt to institutional frameworks ("boiled frog phenomenon"), emphasized the importance of financing rules, and argued for an approach which would **establish well-generalised models of institutional reform while simultaneously cutting the "supply line"** to anachronistic institutions. A crucial element in establishing such a reform would be to provide training for decision makers, staff working in the services, but also users (empowerment).

There was an overwhelming agreement that the Expert Group itself should not work only on reform of "institutional care" but rather on that of "long-term care" in general, or indeed that it should define its goal in positive terms as "promoting autonomy, dignity and independent living" (also mainstreaming education and employment) . Jan JARAB promised to explore whether this could be done in the process of formalisation of the group's status; he pointed out that this could be in the title of the final report, which would be probably more visible than the name of the Expert Group itself.

2. Debate on instruments

The opening statements were followed by a debate on instruments which can be used to support change. The following were mentioned:

- **Open Method of Coordination in the field of Social Protection and Social Inclusion** - improving the reporting by Member States through more focused coordination, precise guidelines (as regards the issue of ensuring equitable access to long-term care, that is among the common objectives Member States have agreed upon under the OMC) (A.-S. PARENT)
- **EU Structural Funds Regulations** - guidelines, potentially even a proposal to change the Regulations in the future (Ask ANDERSEN and Ines BULIC pointed out that there is already a non-discrimination clause which should be used, but others were not convinced that it would be easy to persuade key stakeholders about such an extensive interpretation of discrimination which would make institutional care - as a means of segregating and excluding people from communities - unacceptable)
- **Social Impact Assessments** - guidelines (A.-S. PARENT)
- Bringing the debate into the context of the **internal market**. A.-S. PARENT argued that provision of services (by public, not-for-profit as well as for-profit actors) is becoming part of the internal market, yet without the protection which is offered in other circumstances (e.g., to consumers in the circulation of goods), and this needs to be addressed with **guarantees for the quality of services**, and systems of control thereof. The response from other participants was cautious. Luk ZELDERLOO, in particular, advocated caution on this point, warning that the Expert Group should not be seen as trying to address the issue of SSGI (social services of general interest) through a back door.
- **Public procurement rules** - more and more Member States "procure" social and health services, therefore procurement rules could become a very important tool when developing community based services (L. ZELDERLOO).

- Using and promoting the **existing international human rights instruments**, e.g., International Convention on the Rights of the Child (Anna ZITO), International Convention on the Rights of Persons with Disabilities.
- **High Level Group on Disability**: Member States have chosen independent living as a priority for exchange of good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities. The Ad Hoc Expert Group could make use of this reporting exercise and asking further support from the HLGD. Possibilities of further cooperation will be explored by J. Pfeiffer on the next meeting of the HLGD on 1 April (Silvio GRIECO).
- The **new EU Disability Strategy** from 2010: outcomes of the Expert Group work could feed into the new Disability Strategy (to be probably launched in the second part of 2010), in particular as regards the priority of independent living (S. GRIECO).
- The **new EU Strategy on the Rights of the Child** from 2010 (A. ZITO).
- Initiatives within the context of the **European year for combating poverty and social exclusion** (2010) and the **European year of volunteering** (2011) (A.-S. PARENT).
- Follow-up initiatives to the French Presidency Conference on combating Alzheimer and **COM Communication on a European Initiative on Alzheimer's and other dementias** (Jorge PINTO ANTUNES).

3. Expert Group Report and ways to get there

Jan JAŘAB outlined that the Commissioner envisages a report from the Expert Group which would be handed over to him in October at the latest. The report should be relatively short, easy to read, summarizing ("distilling") the key messages from the experience of the respective Members. It should contain:

- **A general descriptive part**
- **A set of broad policy recommendations applicable to all four categories of end users ("Common Basic Principles")**
- **A set of specific recommendations addressed to the Commission** (as in part 2, above)

There was general agreement on this structure. As to the process, it was agreed that there would be two meetings before summer:

- No 1 - end of April or early May 2009, with first contributions sent by the Members at least 7-10 before the date of the meeting, to be compiled/summarised by the Secretariat);
- No 2 - early or mid-June 2009, to discuss first draft of the Report.

Several other conclusions were also made:

- The Report should not aim at providing new research, but it should contain **references to key existing studies** in all the fields concerned.

- The Report could/should also deal with **identified knowledge gaps** - particularly in the recommendations of the second type, those addressed to the Commission for further use, where proposals for future research would be made¹.
- **If particular processes (in the European institutions) need to be entered already during the phase in which the Report is being prepared, it can be done in parallel** - i.e., if the Group agrees on a particular recommendation which should appear in the Report, it can already feed it into parallel processes several months earlier.
- **Optional ad hoc meetings on more specific subjects** can be arranged during the period of activity of the Group, ideally on the same dates as the regular meetings. (*The brainstorming with Heads of Units from DG EMPL and DG REGIO and their geographic desk officers on the use of ESF and ERDF in Bulgaria, attached to the 1st meeting of the Ad Hoc Expert Group, is one such example.*)
- It appears useful to contact and involve as observers also representatives of DG INFSO ("ICT for inclusion" Unit) and possibly DG MARKT (there was not full consensus on the latter).
- Contacts with projects financed elsewhere by the Commission, namely from the SANCO health programme (projects PROMO and ITHACA) and DG INFSO (ICT and Ageing projects and AAL projects), should be encouraged.

The proposed dates for the April/May meeting and for the June meeting will be circulated ASAP by the Secretariat.

Jan JAŘAB, Silvio GRIECO

¹ In this context, Luk ZELDERLOO made the first proposal already, namely to carry out a legal analysis on Member State legislation which promotes institutionalisation (even though it may not be wholly intentional, e.g., in creating security criteria which other forms of care than large residential institutions cannot possibly meet). Jan JAŘAB suggested that similar proposals can be made already during the year, though it is not very likely that any new study could be launched before the end of the mandate of the current Commission.