Meeting record

Record of informal meeting on de-institutionalisation and transfer to community-based care

14 February 2012

1. PARTICIPANTS

JUST.D3 (persons with disabilities)
EMPL.D2 (Inclusion of disadvantaged groups, linked to recommendation on child poverty, active inclusion, PROGRESS funding, long-term care)
EMPL.E4 (Hungarian desk)
EMPL.E1 (coordination unit for the ESF)
EMPL.F4 (Slovak desk)
EMPL.F4 (Polish desk)
SANCO.C4 (health determinants)
REGIO.D2 (thematic coordination),
DG ELARG.B1

2. BACKGROUND

The meeting was convened by DG Justice (Fundamental rights and the rights of the child) with a view to arriving at a shared understanding of standards and benchmarks for the
broad topic of de-institutionalisation, or transition to community-based care, especially in the light of the fact that many DGs are involved in this topic in one way or another. The aim is to ensure that our collective work in this area aims at real improvement of the situation of people and that recognised standards are respected. The focus must be on the people concerned, not the numbers.

DG REGIO gave an example of Bulgaria: Big programme on childcare institutions; post-communist childcare system remains, with 100s or 1000s of children. Growing numbers of people are institutionalised because of poverty. The aim is to provide community-based care and foster care, COM is financing (further to Bulgaria’s detailed action plan) the upgrading of institutions in bad conditions, training, post-DI measures, in some cases building community-based care.

DG EMPL gave an example of Hungary. HU: ERDF money focussed on modernising institutions; another proposal for big institutions, transition, family-like conditions. It is not enough to invest in infrastructure and downsize institutions, and essential to finance ESF activities in parallel that prepare beneficiaries and staff for transition and the community also, in terms of welcoming community-based care. It would be useful to ask MS to link and cross-finance all activities. They could ask MS to combine projects and resources, for more holistic projects. In HU, for children, there are not too many big institutions, but rather small units, or foster care. It makes sense to use ESF money to train foster parents, or to promote inclusion in schools.

DG JUSTICE.C1 said that children should not be taken into care or institutionalised because of poverty (help should be given to families); this contravenes the UNCRC and underlined the necessity to have gate-keeping for institutions. As discussed at the last DI meeting, some MS legislate on the minimum age for persons entering an institution (e.g. no children under 4, etc.) and a proper system of checks and safeguards should be in place to prevent institutionalisation. As a rule, young children should not be placed in institutions.

DG SANCO said that for persons institutionalised with severe mental health problems there are some advocates for absolute closure of all institutions (including psychiatric institutions), while a more scientific debate favours a combination of institutional and community-based care to avoid the creation of other problems such as homelessness, etc. Pure de-institutionalisation might be harmful; there must be alternatives to closure of institutions. It is not only about numbers, but more about approaches and social inclusion.

DG REGIO said that a guiding principle is that EU funding must not cause harm. With its focus on infrastructure, DG REGIO wants to avoid maintaining large institutions but is sometimes obliged to finance upgrades to those in very poor condition as an interim measure, since institutions cannot be closed down overnight. It is also somewhat easier to push for reform in the Central and Eastern EU MS, through the use of structural funds. The situation in Western EU MS is different. While the overall level of care provided tends to be much higher, institutionalised culture still prevails, with the same consequences as elsewhere. Structural funds can be used for de-institutionalisation, but in most cases these Member States use their national budget for these actions.

DG JUST.D4 said that in the disability strategy, some of the actions listed for 2010-2015, such as training and a toolkit, may well be addressed by the DI group, in the context of informal cooperation.
DG JUSTICE.C1 said that standards should also cover the key aspects of monitoring and inspection, participation and exchange of best practice and we should all have an eye on this.

3. **BENCHMARKING EXISTING STANDARDS AND GUIDELINES**

DG Justice had circulated a list of relevant standards and guidelines (see Annex). The list focuses mainly on standards for children, given DG JUST.C1’s remit. The standards focus on quality of care, individual and personalised treatment, participation and involvement of the care beneficiary in planning, implementing and deciding on their care and also on monitoring and inspection and it is likely that they can easily be adapted for other target groups.

**Action point:** It was agreed that DG Justice would ask if the NGO expert group had similar sets of standards for other target groups (disabled, elderly) and circulate them (Post meeting note: request made to Eurochild/SOS Children’s villages/Lumos). It was agreed in principle that explicit inclusion of relevant standards in the expert group chaired by Lumos (hereafter “the DI group”) guidance would be welcomed.

4. **FRAGMENTED DATA COLLECTION AND AVAILABILITY OF APPROPRIATE INDICATORS**

Participants discussed thresholds and indicators based on numbers of persons vis-à-vis indicators on quality, given that institutionalisation can occur even in smaller residential facilities. Indicators that tackle the quality aspects of depersonalisation, rigidity of routine, block treatment and social distance (as highlighted in the report of the ad hoc group in 2009) might usefully be developed, e.g. on skills and qualifications of staff, training, monitoring and inspection, participation of beneficiaries in decisions affecting them, etc. The Convention on persons with disabilities places emphasis on issues such as access to services, opportunity for independent living, etc.

DG SANCO will launch a joint action work package for interested Member States. This work will be of a practical nature, identifying challenges and situations in MS, for care for people with severe mental disorders. There is also an RTD-financed assessment tool for quality of care, this tool could complement standards and guidelines as it looks at outputs. The tool is available via the internet, for use by any clinical institutions. It could possibly be adapted for other groups.

*Post-meeting note: DG SANCO: The study referred to was the DEMoBInc study. Please find more info about this FP funded study under the link:*
http://www.ucl.ac.uk/mentalhealthsciences/researchgroupsareas/demobinc

*A deliverable from the study is the QUIRC instrument to measure and benchmark quality of care on the basis of a questionnaire, which is available online:*
http://www.quirc.eu/

*The project leader was [name redacted] (http://www.ucl.ac.uk/slms/people/show.php?personid=535)*
DG REGIO carried out a stocktaking exercise in 2010-11, to gain an overall picture of institutional care in MS; they would have to contact Ministries to update this; they have some data on programmes financed, but this is not systematic. Indicators are missing.

DG EMPL.E1 considered that it would not be possible to oblige MS to collect harmonised data or to develop or implement specific indicators. The inclusion of relevant indicators in the DI group guidance would seem to be the best option. DG EMPL will have data on the number of participants covered and DG REGIO on the number of institutions (albeit without a breakdown as to type of institution). DG EMPL.F4 considered that it would be useful to have examples of good indicators.

DG JUSTICE.C1 said that a recurring problem is to correctly identify which projects and programmes covered children and it would be useful if attention could be paid to including specific information on target groups etc., when reading strategies, programme outlines and plans, negotiating with Member States.

DG JUSTICE.C1 said that data which would give a picture of the quality of care is needed. Not only pure numbers on the number of beds, or persons in institutions, but rather information on skilled carers, training provided to staff, monitoring measures, how people in institutions are consulted and involved in the decisions that affect them, etc.

**Action points:**

**DG SANCO** will provide the link to the tool for circulation and it should also be sent to NGOs. (Done, see above.)

**DG JUSTICE.C1** will check with Lumos what work is underway on indicators. *(Post-meeting note: Lumos will look into what they can do there and take on board the need to focus on quality rather than quantity.)*

5. **STRONG FOCUS IN ALL GUIDELINES ON PARTICIPATION**

DG JUSTICE stated that in all the guidelines, there is strong focus on the need to fully involve the persons concerned, be they children or other, in planning, decision-making, implementation, monitoring and follow-up of decisions that affect them.

6. **MEETING CONCLUSIONS**

The DI group has an indicative planning of end-March for information consultation of the Commission on the first draft, followed by an open meeting in mid-April to gather our views.

Some participants asked which DG is chef de file for de-institutionalisation. DG JUSTICE.C1 said it lays no claims to being chef de file, and had convened the meeting with its perspective on children's rights, some concerns around standards to be adhered
to, and also to ensure that people concerned end up better off as a result of COM's work, especially given the number of DGs involved.

It is not clear which DG, if any, is chef de file. Aside from any discussions that may take place on a lead DG, participants agreed that they could usefully meet again to discuss the draft guidelines when we are consulted and work informally together to ensure the best possible outcomes for the target groups concerned.
Annex

List of relevant standards and guidelines to be taken into account for de-institutionalisation:

**Alternative care:**
- UN Guidelines for the alternative care of children: [http://www.refworld.org/docid/4c3acdl62.html](http://www.refworld.org/docid/4c3acdl62.html)

**Relevant reference documents and standards:**
- European declaration on the health of children and young people with intellectual disabilities and their families (signed by WHO, Unicef and RO Min for Health, 26.11.2010)
  - WHO Declaration Better health, better lives: children and young people with intellectual disabilities and their families.

- Quality4Children Standards for out-of-home childcare in Europe (and see also the toolkit) [http://www.quality4children.info/navigation/cms_id.31.nodedid.31._language.en.html](http://www.quality4children.info/navigation/cms_id.31.nodedid.31._language.en.html)
  (There's also a comparison by Nigel Cantwell of Q4C and the UN Guidelines)
Council of Europe recommendation on children living in residential institutions (2005) and follow-up:
http://www.coe.int/t/dg3/familypolicy/enfance/resinstitutions_en.asp

Book for children and young people in care: discover your rights!

SOS Children's villages: Quality care counts
http://www.sos-childrensvillages.org/About-us/Library/Pages/Quality-Care-Counts.aspx

SOS Children's villages: ageing out of care (report, background reading)

The SOS Children's villages I matter campaign (youth empowerment/participation project)
http://www.sos-childrensvillages.org/About-us/Library/Pages/Facts-and-figures-that-matter-copy.aspx