

Health systems and long-term care for older people in Europe Modelling the interfaces and links between prevention, rehabilitation, quality of services and informal care

Feedback and comments by participants of the final conference Baden, 14 October 2011

What I take home from this conference...

- ... that you can overcome the social/health care divide and the divide between formal and informal care with good initiatives like those presented in the market place.
- ... that we have enough ideas and results now we have to make it stay and develop further!
- ... that there is a need for an "in-between" social and health care services.
- ... that we have to put the evidence into practice!
- ... that innovation is constantly going on!
- ... that this project/conference was very practical and very useful for the end-users: older people in need of care!
- ... Thank you for creating a vision for long-term care (empowering policy-makers as well as caregivers)!
- ... Implementing parts of this vision looks like a warm blanket round older people in need.
- ... The examples presented at this conference speak of transparency, directness and resultoriented work.
- ... Foster publicity and action at European and national levels by linking INTERLINKS with the European Year of Healthy Ageing!
- ... Use, fill and continue the INTERLINKS website!
- ... EU should focus on implementation research!
- ... There are parallels between pooled budgets in the UK and integrated provision (Integrationsversorgung) in the German health care system
- ... that problems in each country are quite similar and working together is an efficient way to solve problems
- ... Look different at older people: What can they mean for our society, instead of a burden? (Valuable care!)
- ... contact between countries to implement good examples new networks

... and a short note from Ariela Lowenstein (Israel):

"First, I want to thank you for a very intriguing project and a challenging conference. The most important thing that I learned was that striving for integrated care might be achieved, hopefully sooner than later. Second, we should all try to 'push' for a better balance between informal and formal care. Good luck!"

What is needed to further develop long-term care in Europe?

· More of these market places!

Recommendations "informal care"

- Informal care is valuable: policy-makers must accept that they have to invest in informal care.
- We need complementarity in moving forward more support for carers in many different ways, e.g. culture, work ...
- It must be a free decision to care or not to care formal services must be available.
- Carers' organisations must be involved in the debate on LTC.
- Joint education and training of health and social care professionals AND family members (informal carers) in long-term care (example CD course of German Alzheimer society).

Recommendations "user perspective"

- People in need of LTC have a right to live an autonomous life as long as possible: selfdetermination until the end of life.
- Human rights must be the guiding principle in LTC.
- Person-centred orientation of long-term care (person-centred approach)

Recommendations "improved implementation"

- Dynamic & ongoing cycle of implementation, innovation, research and teaching
- More coordination and cooperation between health and social care systems!
- Links between services: how to empower patients/carers to assume the role of coordinators.
- Harmonise legislation to make long-term care seamless
- No new types of provision should be started without the necessary preconditions for their implementation (mainstreaming)
- Clarify responsibilities at administrative levels
- Re-think how institutions can be used in terms of long-term care
- More involvement of caregivers in developing innovations
- Certainly no EU legislation!
- Do not forget about acute situations in long-term care!
- Introduction of new professions: patient/client advocates, case managers, social brokers.
- A roadmap for clients: What? Where? When?
- Good practice exchange for providers at EU level
- Quality of Life as an outcome?

Recommendations for research

- Develop a list of indicators for informal care
- We need a framework for informal care standards in LTC that are based on the judgements of cared for older people
- Instruments for needs assessments should be consistent and transferable to other settings
- Research on socio-economic effectiveness of informal care
- Cost-benefit analysis of the support to informal carers: how can informal care save money?