

‘Bringing an end to institutionalisation of children with disabilities in the EU’

European Parliament, 4 March 2008

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Statement of the European Coalition for Community Living European Parliament, 4 March 2008

The European Coalition for Community Living (ECCL) welcomes the debate organised in the European Parliament on ending institutionalisation of children with disabilities in the European Union. Although today’s event focuses on the situation in Bulgaria, this country is one of many across Europe that continues to place children with disabilities in long stay institutions, often for life. This briefing sets out the steps that ECCL believes must be taken at European and national levels in order to end this unacceptable practice.

Scenes from the Mogilino social care home, shown in the documentary *Bulgaria’s Abandoned Children* are shocking. Viewers witness the horrific consequences of the practice of placing children with disabilities in institutions. Not only are the children denied education or any meaningful activity, they also suffer from severe malnourishment and longstanding neglect. There is also the suggestion that some children have been physically and/or sexually abused. Three children die during the course of the filming. Sadly such scenes are not unique.

Institutionalisation of disabled children: an abuse of human rights

A report funded by the European Commission, entitled *‘Deinstitutionalisation and community living – outcomes and costs: report of a European Study’*, published in November 2007, estimated that more than 1,2 million people with disabilities in the EU, including children and young people, still live in institutions¹. The reason why so many disabled people are institutionalised is because in many European countries there are little, or no, community-based services for people with disabilities. Accordingly, institutions

are often the only available option. The report confirmed that institutional care is often of an unacceptably poor quality and represents a serious breach of internationally accepted human rights standards. Community-based services, when properly established and managed, deliver better outcomes in terms of quality of life and ensure that disabled people can live as full citizens².

The film *Bulgaria's Abandoned Children* is not the first evidence of the appalling conditions, and the serious human rights abuses that take place within Bulgaria's institutions for disabled children and adults³. Reports on the situation for disabled people in institutions in other Central and Eastern European countries have highlighted similar serious concerns. For example, a recent documentary on conditions in the Czech institutions for children and adults with disabilities showed how cage beds are still being used despite international condemnation and a legal ban imposed last year⁴.

Institutionalisation of disabled children leads to serious delays and impairments in their personal development. Disabled children who grow up in an institution have more difficulties in participating in society at a later stage in their lives⁵.

Despite the recognition that good-quality community services must be developed as alternatives to institutional care, new institutions are still being built in the EU. Furthermore, in countries like Romania, despite a severe lack of community-based services, EU structural funds are used to build new institutions, rather than support the development of needed alternatives.

Right of children with disabilities to live in the community

Article 23 of the UN Convention on the Rights of the Child makes it clear that disabled children, regardless of the type or degree of their disabilities, have the right to live in the community. Article 19 of the UN Convention on the Rights of Persons with Disabilities recognises the equal right of all disabled people to live in the community, with choices equal to others, and requires States to:

“...take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.”

The EU Disability Action Plan 2008 – 2009 also promotes community based services as a means to facilitate social inclusion of people with disabilities⁶.

The only way these rights and principles can be put into practice by the Member States is by developing comprehensive, quality community-based services. These must be available to *all* children with disabilities, including the most vulnerable children with complex dependency needs.

Need to develop alternatives to institutions

The process of developing comprehensive and good quality community services so that the institutions can be closed takes time and requires careful planning. However, if we want to stop hearing reports such as those from Mogilino, the process of developing alternatives to institutionalisation needs to begin without delay.

To develop quality community-based services, as an alternative to institutional care, Member States must have a clear vision and take leadership in the process. The alternative care system that is envisaged must be considered in detail so that poor services in institutions are not replaced by something equally bad in the community. It is also crucial that governments work in close collaboration with people with disabilities, their representatives and families throughout this process.

Steps that the Member States can take to take this process forward include⁷:

- **Adopt policies in favour of inclusion.** It is important that such policies are accompanied by a timetable and plan for transition from institutions to services in the community. Governments should also make a commitment to stop building new institutions;
- **Develop legislative support for inclusion.** This includes adopting legislation that promotes the social inclusion of disabled people, ratifying the UN Disability Convention and prohibiting the use of public funds to build new institutions;
- **Include people with disabilities,** their families and representative organisations in policy making and other stages of transition to community-based services;
- **Create innovative services.** Member States should fund the development of services in the community, using ordinary housing and providing the level of staff support based on each person's needs.

The European Commission and the European Parliament have an important role to play as well, and should encourage and support the Member States in taking the reform process forward.

Steps that the European Commission and the European Parliament can take include:

- Ensure that the EU funding is not used to further the social exclusion of Europe's disabled citizens by sustaining the existing institutional system for people with disabilities. Rather, the investment into comprehensive, quality community-based alternatives to institutions must be promoted;
- Promote, and regularly evaluate the progress made by the Member States towards, the development of community-based services and the closure of institutions when monitoring the implementation of the EU Disability Action Plan by the Member States;
- Use the process of accession of new Member States to the EU to ensure that the rights of people with disabilities are respected and that alternatives to institutions are being developed;
- Ratify the UN Convention on the Rights of Persons with Disabilities and the Optional Protocol to the Convention;
- Encourage the Member States to promptly ratify and implement the UN Convention on the Rights of Persons with Disabilities, together with its Optional Protocol.

¹ See *De-institutionalisation and community living – outcomes and costs: report of a European study*, written by Mansell J, Knapp M, Beadle-Brown J and Beecham J, Tizard Centre, University of Kent, 2007. Available at www.community-living.info/?page=257.

² See the article 'A Blueprint for Community Living', Newsletter of the European Coalition for Community Living, Issue No. 5, December 2007. Available at www.community-living.info/index.php?page=236.

³ See, for example, *Bulgaria: Far from the Eyes of Society*, Amnesty International, 2002 and *The Archipelago of the Forgotten: Social Care Homes for People with Mental Disorders in Bulgaria*, Bulgarian Helsinki Committee, 2005.

⁴ See the article 'Filming reveals Czech children still caged', BBC News, 15 January 2008. Available at <http://news.bbc.co.uk/1/hi/world/europe/7189556.stm>.

⁵ See, for example, UNICEF/Innocenti Research Centre Report *Children and Disability in Transition in CEE/CIS and Baltic States*, 2005, page 14. Available at www.unicef.org/ceecis/Disability-eng.pdf.

⁶ See Communication from the European Commission on the situation of disabled people in the European Union: the European Action Plan 2008-2009 (COM/2007/738), page 5.

⁷ These recommendations were taken from the report *De-institutionalisation and community living – outcomes and costs: report of a European study* (see endnote 1).