

Third Croatian Symposium on Early Childhood Intervention
University of Zadar
September 26-28, 2013
Team around the Family – Myth or Reality?

Helmut Heinen
Managing Director of the Office of the German-speaking Region of Belgium for
People with Disabilities

Dear colleagues,

first of all, I wish to thank you very much for inviting the Council of Europe to the very important symposium on the topic „Team around the Family – Myth or Reality?“.

I am delighted to be here with you, and I am very pleased that you have combined the symposium with the yearly conference of the European Association on Early Childhood Intervention – EURLYAID. Indeed, I was the co-founder of this European Association in 1988, 25 years ago. The Council of Europe asked me to attend this conference to present the Council’s most important initiatives related to the present symposium. First of all, allow me to give a short outline on the institution:

The Council of Europe is a political organization which now numbers 47 member states with a total population of more than 800 million people. The main aims of the Council of Europe are to reinforce democracy, human rights, and the rule of law and to develop common responses to political, social cultural and legal challenges in its member states. Disability-related activities lie at the heart of Council of Europe activities in favour of human rights. They are guided by the Council of Europe Disability Action Plan and the United Nations Convention on the Rights of Persons with Disabilities.

Various expert groups have looked in great depth into the needs of people with disabilities. A major result of this work was that in the Council of Europe Disability Action Plan, early intervention has been recognised as a necessity – for the first time in a superior text. And it has contributed to the fact that early childhood intervention has become more evidence-based in the services destined to meet the needs of children with disabilities and their families.

The Disability Action Plan underlines that one objective shall be to ensure, in particular, high-quality early intervention, a multi-disciplinary approach, from birth, including support and guidance for the parents.

Among the specific actions by the Council of Europe member states, the Disability Action Plan names the following actions:

- to ensure that notification of the disability, whether it occurs before or after birth or after an illness or accident, is made under conditions guaranteeing respect for the person concerned and the family and ensuring clear, comprehensible information and support for the individual and his or her family ;
- to recognise the need for early intervention and thus establish effective measures to detect, diagnose, and treat impairments at an early stage, and also to develop effective guidelines for early detection and intervention measures.

The Disability Action Plan is in force until 2015, but already now, there are intentions to work out a Plan II. As you all know, the pathway to inclusion needs more time than initially expected.

Besides the Disability Action Plan, the Council of Europe has also adopted several other Recommendations related to the topics of the present symposium. It has given particular attention to the situation of women and girls with disabilities (Recommendation (2012)6 of the Committee of Ministers to member States on the protection and promotion of the rights of women and girls with disabilities). It must be noted that in reality, especially women and girls with disabilities risk to suffer multiple discrimination based on disability and gender. The aim is to achieve full equality, participation in society and enjoyment of all rights on an equal basis with others. Therefore, the Council of Europe recommends to adopt the appropriate legislative measures and to conduct other positive actions.

In relation with your work, the Recommendation on deinstitutionalisation and community living of children with disabilities (Recommendation (2010)2 of the Committee of Ministers to member states on deinstitutionalization and community living of children with disabilities) is even more important. It says that the own family is the natural environment for the growth and well-being of a child. It thus defends that all disabled children should live with their own family, unless there are exceptional circumstances which prevent this. It also stresses that parents have the primary responsibility for the upbringing and development of the child. Parents should choose how to meet their child's needs as long as their decisions are seen to be in the child's best interests.

The Recommendation also accents the state's responsibility to support families so that they can bring up their disabled child at home and, in particular, to create the necessary conditions to implement a better reconciliation of family and working life: the state should therefore finance and make available a range of high-quality services from which the families of children with disabilities can choose assistance adapted to their needs.

To make deinstitutionalization succeed, member states should phase out institutional placements and replace these forms of care with a

comprehensive network of community provision. Community-based services should be developed and integrated with other elements of comprehensive programmes to allow children with disabilities to live in the community.

The Council of Europe Charter on Education for Democratic Citizenship must also be mentioned here. It follows from this Charter that childhood and adolescence are the key stages of life in which to train young people for maximum autonomy and independence in adulthood. Children and young people with disabilities should therefore be allowed to grow up together with their non-disabled counterparts and be free to make their own choices and express their opinion on any matter concerning them. To exercise these rights they should be given assistance that is in keeping with their needs and their age.

In reality, however, the situation is quite different. Too many children and young people with disabilities in Europe still live in institutions and are separated from their family. Furthermore, many of those who do not live in institutions are not yet present in society and in people's minds. In many member states, the right to behave as active citizens and to be able to take part in decision-making processes is still very rarely applied to children and young people with disabilities. They still too frequently encounter a whole series of obstacles which prevent them from participating and being recognised as fully-fledged citizens. Almost half (46%) of all EU citizens consider that individuals are discriminated against on the grounds of disability.

Whereas some children and young people with disabilities can express their opinion and their dissatisfaction, those with severe mental impairments are not able to do so because of their problems in expressing themselves and understanding. Responses to their needs in terms of exercising their rights cover a very broad spectrum, ranging from full

assistance to autonomy. Support must accordingly be personalised depending on their capabilities and their age.

Recently, a new Recommendation has been prepared on ensuring full inclusion of children and young people with disabilities into the society. The Committee of Ministers will discuss this Recommendation in early October 2013. A report accompanies this Recommendation. It describes the Recommendation's background, highlights the challenges and consolidates the policy responses for protecting and promoting the rights of boys and girls, young men and young women with disabilities facing systemic barriers, negative attitudes and social exclusion. It sketches the main elements for creating a completely inclusive society in which children and young people with disabilities are actively involved and where their needs and expectations are taken into consideration.

Children and young people with and without disabilities are the future of society. They must be allowed to grow up together. Non-disabled children will quite naturally learn about difference, live with it and respect it. They will be the stakeholders and guarantors of a society which values diversity. These efforts are also aimed at a sustainable strategy for an inclusive society.

The report points out that all children with disabilities should be able to live with their own families, barring exceptional circumstances.

In order to achieve this, it is vital to listen to them, take them seriously and promote their self-esteem, as well as supporting and reinforcing their families in their capabilities (empowerment). Therefore, the report suggests to the member states that the transition from institutionalisation to an active life in all sectors of society also requires that early intervention services and other high-quality local services be set up and geared to advising and supporting the children and their families. This also necessitates respite services able of occasionally relieving the families.

Education can be regarded as the basis for the inclusion of children with disabilities in society. Inclusion in education necessitates a comprehensive approach to the whole school system. Schools must adapt to the students' educational needs, and not the reverse.

A recent study by the European Association of Service Providers in Disability (EASPD) in 10 European countries shows that the number of pupils receiving an inclusive education is on the increase. At the same time, however, the number of pupils in special education is not decreasing. Does this result from an increase in the number of children and young people with disabilities in society, or from an urgent need to tailor curricula to individuals and review education strategies to stop pupils dropping out?

Major obstacles are brought about by inflexible systems which leave no room for adapting methods or tailoring curricula to individuals. For teaching staff to subscribe fully and firmly to this change in approach, it is essential for them to be trained, guided and supported.

The fact remains that there is a risk of inclusion not being applied to those children with more severe intellectual impairments, additional disabilities or an autistic spectrum disorder.

Professionals and other stakeholders in these sectors should have compulsory additional training in « inclusive competences » in order to require the requisite strategies, methods, resources and willpower to ensure the success of this ambitious project. We must take up this challenge in order to build a Europe for and with all children.

In this context, the member states should promote the development of early intervention services tasked with providing quality education and rehabilitation programmes, meeting the specific needs of children with disabilities from an early age and offering support designed to enhance parental skills.

Moreover, member states should ensure that:

- a high standard of training is provided for staff specialising in the disability field and that the training courses of all educational and support staff contain one module or more, whose aim is to teach them skills related to inclusion

Member states should ensure also that:

- parents are involved as partners in every educational process involving their children and that effective support and respite services are provided for them so that they can continue to shoulder their responsibilities and that institutionalisation can be avoided.

The report underlines the developments still needed and the measures to be taken so that these children can be actively involved in society. Social inclusion is a societal process which requires a broad consensus within all stakeholders must co-operate.

For children and young people with disabilities this process requires such a major change of attitudes and mentalities that it must begin at a very early age in order to have a lasting effect.

Mainstreaming services (called in different countries: services of general interest) must open up and adapt in order to be able to meet the needs of all. And the specific additional services should be available to families close at hand.

Dear colleagues, Early childhood intervention is one of the elementary milestones of this challenging and valuable construction site.

From all these guidelines, it clearly arises that the path may only be successful if it is developed "with the families".

On behalf of the Council of Europe, I wish you an enriching exchange and discussion during the conference and also after it. I am convinced that this conference will contribute to ensure that empowering families and professionals' and parents' working in partnership will no longer be a myth but become - every day - more and more reality.

I very much thank you for your attention.

Zadar, 26 september 2013