



European project on Down Syndrome reveals real needs of DS parents in Bulgaria and Hungary

Kendro Merimnas Oikoyenias kai Pediou (KMOP)¹ is participating in an innovative European project that focuses on the needs of persons with Down Syndrome. Titled ***Re-investing expertise: expansion of professional training for educators and parents of children with Down's Syndrome – Re-PoD***, this two-year trans-national project is led by the Greek NGO “Family and Childcare Centre”, and further the consortium is supplemented by additional partners from Greece, Bulgaria and Hungary.

The main goal of the project is to revise and adapt an innovative training tool developed in a previous Leonardo da Vinci Development of Innovation project (PoD project) for family members and professionals to help stimulate and educate persons with DS throughout their lifetime. This will serve to improve the quality of life of persons with DS and help them achieve maximum autonomy.

The project has now come half way through implementation, with its initial major phase completed; namely an in-depth analysis of the needs of families of persons with DS in both Bulgaria and Hungary. The consortium has gone to great depths to study the full range of relevant areas, including health, socio-affective development, autonomy, education, socio-economic resources, social involvement and sexuality, in order to establish what the actual needs are of families with DS children.

The research, which included both quantitative and qualitative analyses, was divided into age groups; ranging from early intervention (0-6 yrs), to schooling years (6-18 yrs) and adulthood. While the early ages required aspects of primary education and childcare health programme to be considered; the schooling years incorporated relations with the school and socio-economic resources, and the adulthood phase focused on professional training and employment, ageing processes/ issues related to premature ageing and socialisation. In addition to the active involvement of family members of persons with DS, professionals from public and private institutions, from the medical and educational field, that focus on persons with DS were also involved.

The results from the first phase of implementation have been rather enlightening. Both Bulgarian and Hungarian reality proved to be striking in their lack of information on issues related to health (specific health plans to follow in each development stage), education (structure, characteristics and entry procedures), to raising awareness of legal issues and rights related to grants (procedure of disability certificate) and financial assistance and further to information on organisations and bodies that support and facilitate the social participation of people with Down syndrome.

¹ KMOP is a social NGO with humanitarian values that is driven by the belief that every individual has the potential to enrich society. Established in 1979, KMOP has almost three decades of experience in projects targeting vulnerable population groups in danger of social exclusion, such as persons with physical disabilities and mental disorders, school drop-outs in compulsory education, unemployed women and youth and those with low professional qualifications.

Families surveyed addressed that communication between various professional involved in issues related to people with DS, needs to be facilitated and empowered. Families demand more information and more guidelines from professionals in regard with the various stages of their children's socio-affective development, revealing a need to learn more about the evolution and development typical of DS. They need guidance so as to promote autonomy from early ages, as well as other cognitive skills. There was consensus on the particular difficulties posed by the transition phases; from primary to secondary education and transition to adult life. Overall, there is an expressed need for support to the family throughout the entire life cycle, with particular assistance in times of transition – puberty, adolescence, adulthood – and changes in their environment – schooling (primary to secondary; mainstream to special needs school) and entering a vocational training centre.

Among all negative aspects, families also speak of the practical experience of diversity, how family bonds have strengthened. What is more, another positive aspect related to the development of a child with DS is that all the different stages in development are experienced more intensely and achievements of the child are savoured more than those of a previous, 'normal' child.

Building on the research done and responding to the established needs, the next step in the project is now implemented and involves the adaptation of those areas of the already developed PoD tool, so as to design and pilot the updated training tool, which will be in accordance with both the needs of the families in both countries and the national context and framework in respect. This tool will take the form of a DVD (supplemented by a booklet and a CD), which will be distributed to families of persons with DS, as well as to various stakeholders including professionals from relevant institutions and agencies.

The tool that will be designed will use simple, positive language and will include different testimonies by professionals as well as children themselves, so as to reflect all the realities faced by people with DS. There will be a general overview of all the stages of development in a DS child offering sufficient information to banish common myths about the condition.

Providing images that show how problems can be resolved, coupled with home videos that provoke changes of attitude, the DVD, while aiming to be balanced, will seek to reflect a positive assessment of families with DS children: picturing affective, emotional values, appreciating changes and achievements. It will show families and persons with DS persons performing different types of creative and leisure activities. Professionals will offer types of stimuli, simple exercises to be done in the home. In an effort to deal with the topic of overprotection, the DVD will reflect the need to show the interaction of people with DS outside their own family, and with other children – giving the family the opportunity to see how a DS child behaves without the support of the family. Moreover, the tool will feature options for adult life, and offer information on health and premature ageing for the older age groups, as well as updated information on subsidies and resources available in Bulgaria/Hungary, including relevant application procedures.

This designing phase of the tool is expected to be concluded at the end of 2013 and it will enter its pilot phase in early 2014, with the production and publishing envisaged for later in the year.

Project's website: www.repod.org

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