

*The information in this document reflects the situation when it was written in 2006.
Please bear in mind that some contact information may since have changed.*

EXPERTS IN THEIR OWN RIGHT



The most appropriate word to describe the life situations of parents caring for children with disabilities at home would probably be constrained. Unemployment, lack of job security, single-parenthood and financial uncertainty or poverty are factors which often have a negative influence on the quality of life in these families. In many cases, it is the child's disability, which define the parents' social and personal identities, and mothers often see their role in life as being mainly, or sometimes solely, that of a carer. Valuing and recognising the experience of these parents was at the heart of the French Development Partnership (DP) Conciliation-Famille-Handicap. At the same time, the DP has developed a large variety of activities that support the integration of children and young people with special needs into regular education, training and employment.

In families that are bringing up a child with disabilities one partner, usually the mother has dedicated his or her life to the education and care of this special child. Over years such parents accumulate a wealth of knowledge and skills, based on practical experience, but often also on independent study. It appears that this expertise is not sufficiently well appreciated by the professionals whom the parents encounter in their endeavour to create a life for their child that is as "normal" as possible. Conciliation Famille Handicap aims to make the reconciliation of family and working life a real option for this group of mothers and fathers, in particular, by opening up career opportunities based on the expertise gained as a parent.

PARENTS AS MEDIATORS FOR INCLUSION

The DP has designed a vocational profile and training programme for mediators specialising in integration pathways for children and young people with disabilities. The scheme targets parents, as experts in their own right, but it is also open to different categories of professionals involved in the support of people with disabilities. Around 1000 people took part in the training, which provided a solid base of knowledge about the situation of people with special needs and their specific incapacities and in-depth information about the regular education and training provision and the employment perspectives in the participants' localities. In addition, the future mediators acquired social skills that enabled them to communicate more effectively with people with disabilities, their families and other professionals. The task of the new mediators is not only to help children, young people and young adults towards a more independent life, but also to ensure that there are no sudden changes or disruptions to the pathway that endanger the safe and affirmative environment, which, for people with disabilities, is decisive in the attainment of their full potential. As a first step, the project produced a "syllabus", which collated the necessary competences related to education, training and employment. These competences were validated, and gradually developed, to create a curriculum for mediators that would provide them with the knowledge and skills to foster permanent and sustainable inclusion in variety of different settings. Several Universities have now integrated these courses into their current provision.

MAKING INCLUSION A REALITY

The DP has worked with mainstream institutions such as schools, providers of vocational training and leisure activities and also enterprises, to strengthen their capacities to integrate people with disabilities and thus, to alleviate some of the burden that falls on parents. To achieve this goal, Conciliation-Famille-Handicap has established a network of partners that all have relevant expertise related either to certain disabilities or to specific parts of the education, training and labour market systems. Thus, the DP's activities could address a whole range of crucial issues and it has provided direct help through resource centres (in Alsace and Bretagne), home-based respite support and leisure and art opportunities for children.

In several regions, partners piloted a modular programme for "school assistants" whose task was to improve the integration capacity of primary schools. In the past, students or job seekers could be employed as part-time or full time school assistants by associations with a subsidy from the State. Their task was to help the teacher in the classroom and in all other activities and while some worked with the whole class, others were assigned to only one pupil. Since September 2003, these assistants have been employed by the Ministry of Education on three-year contracts and the DP helps them with the accreditation of their experience as part of their preparation for a University degree. The DP also made active use of that new opportunity to develop the primary school strand of its mediation scheme. *"Our main concern,"* emphasises Alain Bony, the project coordinator, *"is to integrate all our activities and outcomes in mainstream provision, otherwise they will not spread and be funded"*.

The French Palsy Association (IEM) developed a training programme for upper secondary school staff, designed to help these schools create special pedagogical units focusing on the integration of students with disabilities. Another organisation, Epilepsy Euro Service, produced a training module to inform and sensitise different categories of professionals. The module was specifically designed to counteract persistent misinformation, taboos and prejudices against people with disabilities and it has now been mainstreamed by the education authorities in Poitiers.

Most partners are also helping parents to gain more free time and breathing space, through supporting and increasing the autonomy of the individual child or young person. For instance, CRESAM, the Experimental Resource Centre for blind-deaf and deaf Children and Adults, trained professionals and also family members and people with disabilities. CNEFEI, The National Research and Training Centre for Children with Special Needs, provided modular ICT skills to both parents and professionals. In addition, this organisation developed training for the use of "communication interfaces" to help deaf people to become more independent. This included training in sign language for teachers and experts; but also the creation and application of new tools such as computer software. The software allows a deaf person, whenever anybody is speaking, to follow simultaneously on a screen a signing translation and to lip-read the mouth on a virtual face. As many words are not yet translated or universal in sign language, the production of glossaries in specialised domains such as accountancy, law, tourism, geography or citizenship, was another important task assumed by the project. The tools and guidebooks that were produced went through "quality checks" performed by a group representing the beneficiaries. In the 2nd Round of EQUAL, the DP has extended this activity to the Internet and Websourd (Webdeaf) is used to help in translating websites and providing online interpretation, in sign language.

MOBILISING PUBLIC SERVICES TO BECOME MORE OPEN AND MORE FLEXIBLE

Experience showed that there are very few bridges between the public services, institutions and organisations that cater for the needs of parents of children with disabilities. Training for this target group has to take account of their specific needs and this means current provision has to become more flexible to accommodate the time constraints of the mothers concerned. Ad hoc structures may be required in the short term, but in a longer term perspective, it is society as a whole which must consider how it integrates all its members. In the 2nd Round of EQUAL, the new DP ARTDEVIE is focusing on:

- Creating resource and mediation platforms for families and local authorities to promote social integration;
- Setting up mediation groups including parents, people with disabilities and professionals, working in cooperation with Time Bureaux;
- Providing common initial and further training for professionals working in this area;
- Developing the exchange of innovation and good practice between the various municipalities which have signed an agreement that commits them maintain their status as disability-friendly towns.

Contact

Conciliation Famille Handicap
CNEFEI
Alain Bony
58-60, Avenue des Landes
F- 92150 Suresnes
Tel : +33 1 41 44 31 21
E-mail: alain.bony@wanadoo.fr
Website: www.cnefei.fr

ARTDEVIE
GIP Handicaps et Compétences
Alain Bony
102 rue Didot
F - 75014 PARIS
Tel: +33 6 83 10 59 97
E-mail: ltve.gip@wanadoo.fr or
alain.bony@wanadoo.fr

Link to EQUAL database description: [FR-NAT-2001-10370](#) and [FR-NAT-2004-44327](#)
Transnational Partnership: [EIH Networking](#) and [SMILE](#)
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