

# 2012-17 THE ECONOMIC AND SOCIAL COST OF AUTISM

*Autism is classed as one or more Pervasive Developmental Disorder(s) (PDD) which affects the individual in terms of verbal and/or non-verbal communication, social interaction, and which is characterised by restricted and stereotyped focuses of interest.*

*The improvements in identification, the diagnostic criteria and the changes to the international classification have all contributed to a significant rise in the prevalence rate of the condition.*

*Today it affects one birth in every 150, which makes it a genuine public health concern.*

In 1995, recognition of autism as a disability helped to bring the problems and issues faced by people with autism, and by their families, out of the private, family and medical spheres. Autism is now an issue for society as a whole. In France there are between 250,000 and 600,000 persons with autism out of 5 million French people with disabilities.

Knowledge about the condition is continuing to grow, even if progress is still not fully satisfactory.

In 2010 the French National Authority for Health (HAS) produced a review of the current state of this knowledge and together with the National Agency for the Evaluation of the Quality of Social and Medico-social Services (ANESM), prepared a new set of recommended good practices for coordinated educational and therapeutic interventions relating to children and adolescents.

This corpus should now be widely distributed and shared.

It is true that autism does not feature to any real extent in the initial and ongoing training of healthcare personnel, teachers and educators.

The needs and expectations of families are enormous when compared to the

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paucity (up to now) of responses, which now need to be forthcoming in practice.

In terms of diagnosis: although it can be identified before 30 months, the condition is rarely diagnosed before

the age of 6 due to a lack of capacity in screening and diagnostic centres.

Nonetheless, coaching from the youngest age is a factor in the prognosis for autonomy and independence in the person affected by autism.



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The costs of intensive behavioural interventions have to be met by the families meaning that educational equality is not possible for all of the children concerned.

It should be possible for the child to be accommodated from his or her early childhood, and then enrolled in school.

If progress with regard to accommodating children with disabilities, and in particular autistic children, has been made since the enactment of the Act of

**« There is still no educational solution for 13,000 young people with disabilities »**

11 February 2005, only 20,375 young people have been enrolled in schools. In 2010 the State made available 1.4 billion Euros for people affected by autism (680 million Euros for institutional accommodation and health and social care services; 664 million for allowance payments and 55 million for education).

If an effort has been made in the 2nd autism plan with the creation of 4,100 specific places (not yet set up), this effort must be continued with a view to progressively adapting what is on offer to the needs of people with autism.

For their part the départements (departments) have allocated 5.52 billion Euros to the policy of support for persons with disabilities.

**None of this would have been possible without the close involvement of the families and associations, who have been major players in the social advances for persons with autism. ■**

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## SHARE KNOWLEDGE AND TRAIN THE KEY PLAYERS

👉 **The ESEC recommends having training courses for social workers certified by the Autism Research Centres (CRA), whose role should be homogenised throughout the entire country.**

Improve training for all parties involved so that the quality of care is improved by:

- **introducing an immersion course** into the initial training of teachers /educators; **making training compliant** with the recommendations of HAS and ANESM regarding the Continuing Professional Development (CPD) of healthcare professionals; **pooling training schemes** and/or resources; **creating training courses which lead to qualifications** developing training for those working in the Departmental Homes for Disabled Persons (MDPH); **better training for parents** particularly by improving access to paid training leave; **acknowledging all of the roles involved in re-education.**

## ORGANISE AND FINANCE RESEARCH AND PROGRAMMES TO MEET THE CHALLENGES

👉 **The ESEC recommends that current funding should be long-term and that the tax deductions currently in place should be maintained.**

It is also important to:

- **better organise research** both nationally and internationally; **entrust the ANR (French National Research Agency) with an autism programme** with the particular aim of developing the link between basic research and clinical research; **strengthen French expertise** regarding educational and behavioural strategies and arrange for an evaluation of the various practices and tools which are used in the treatment of autism.

## COLLECT DATA IN ORDER TO EVALUATE THE EXISTING SYSTEM

### AND TO DEFINE A REALISTIC AND SOUND POLICY

👉 **The ESEC envisages the implementation of a genuine epidemiology of autism** and to that end is proposing:

- **preparation by DREES (Department for Research, Evaluation, Studies and Statistics)** of a statistical study common to government services as a whole.
- **preparation by IGAS (Inspectorate General for Social Affairs)** of three studies covering the social consequences for families bringing up autistic children; the premature mortality of children and their parents and the cost differences in care between France and Belgium.

## IMPROVE IDENTIFICATION OF THE CONDITION AND REDUCE THE TIME INVOLVED IN ARRIVING AT A DIAGNOSIS

👉 **For the ESEC early identification and diagnosis are pivotal to making progress on care services policy:**

- **to include specific items** in the 9th month health certificate and in the child health record; **allowing the Child and Maternal Protection (PMI)** to carry out a health check on children aged three to four years and to arranging the diagnostic process from 30 months would contribute to the achievement of these objectives; **to propose that the health assurance industry** initiates a diagnostic procedure for adolescents and adults.

## COORDINATE CARE

👉 **Several of the recommendations from the ESEC can contribute to the quality and fluidity of care for each individual affected by autism:**

- **recognise that the families** have a coordinating role in the care provided; **define and determine the role of the CRA** along with that of the other players; **limit the number of failures** linked to age-related barriers; **encourage movement** between the various specialisms in order to make the sector more attractive.

## MAKE LIFE EASIER FOR THE FAMILIES AND

### RESPOND TO THE SPECIFIC NEEDS OF PEOPLE WITH AUTISM

👉 **In order to make life much easier for families the ESEC recommends:**

- **introducing a form of support**, through the consultant, from the time of diagnosis; **creation of a hotline**; **financing home assistance** through the disabled-child education allowance; **registering with personalised compensation plans** for temporary assistance and relaxing the arrangements for « sick child leave ».
- **envisaging regional planning** of childcare places in centres for young children; **developing the links between the « ordinary »** placement structures and the medico-social establishments; **allowing access to centres for early medico-social action** based on a simple medical prescription and reimbursing travel costs would make the provision of care for children easier; **developing places specifically dedicated to autism** within specialised structures and making allowance in budgets for the placement of persons affected by autism, **encouraging a coordinated regional approach** in order to look into the circumstances in which certain patients in psychiatric hospitals could return to medico-social establishments and finally **reimbursing the costs of structured educational support programmes.**

## ENHANCE GOOD GOVERNANCE

- **by entrusting responsibility for disability** to every government department responsible for organising of our society; **by entrusting the implementation of specific plans to a dedicated team**; **by giving the CNSA (National Solidarity Fund for Autonomy) responsibility for guiding and evaluating** the coordination of accessibility and compensation policies.
- At a local level, **encouraging elected representatives to participate in regional health conferences** would facilitate a genuine policy of working together.
- Finally, in the context of Decentralisation Act III, **the decentralised social policies and how they reconcile with the ARS (Regional Health Agencies) should be evaluated.**