

autisme-europe

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autism-europe

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Portrait

Autism Society of Ukraine

Scientific dossier

Secretin and autism

News

Launch of World Autism Organisation



Publication of Autism-Europe
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■ AGENDA

MALLE (BELGIUM)

6 February 1999

Diagnostic and Care of people with autism with average IQ and/or Asperger syndrom
Prof C Gillert, Child Psychiatrist and expert in autism, University of Göteborg, (Sweden)

This conference will be held in English and will be preceded by workshops on behavioural problems, communication, informal researches, adults with autism, etc.

For more information:

Opleidingcentrum Autisme
 Laar 61B
 B - 2140 Antwerpen (Belgium)
 Tel.: +32.3.235.37.55
 Fax: +32.3.236.58.46
 E-mail: OPL.CTR.AUTISM@ping.be

PARIS (FRANCE)

Amphithéâtre of hospital Baudelocque

13 - 14 March 1999

Training sessions organised by: association APECADE "La kinésithérapie précoce en cas de troubles neuromoteurs du jeune enfant"

For more information:

Sécretariat de l'APECADE
 Tél.: + 33 1 42 34 12 12
 poste 3147
 Fax: + 33 1 43 26 12 50

BICKENHILL - SOLIHULL (UNITED KINGDOM)

National Motorcycle Museum Conference Centre

18-19 March 1999

Conference organised by Allergy Induced Autism, focused entirely on the medical aspects of autistic spectrum disorders.

Topics: the immunological defect model; new secretin studies; latest metabolite findings in autistic children; viral connections; the opioid theory explained; drug reactions; auto-immunity in the intestinal tract; gastro-intestinal findings in ADHD children; the sulphation connection.

For more information:

Mrs Meryll Nee
 AIA Conference office
 210 Pineapple Rd, Stinchley
 Birmingham B30 2TY
 Tel./fax: + 44 121 444 6450

ÖREBRO (SWEDEN)

13-15 April 1999

Man, Disability, Life Conditions

7th Research Conference organised by Psychiatry and Rehabilitation. Includes presentations on Autism and Asperger's Syndrome

For information:

Britt Johansson
 Tel.: +46.019.15.72.13,
 e-mail: britt.johansson@orebroll.se

BERNE (SWITZERLAND)

23-24 April 1999

Fédération suisse des associations de parents de handicapés mentaux

International Congress: Changement de Paradigmes et communication - Nouvelles approches de l'accompagnement des personnes handicapées mentales.

For more information:

INSIEME
 Rue de l'Argent 4
 Case postale 827
 Ch - 2501 Bienne
 Tel.: + 41 32 322 17 14
 Fax: + 41 32 323 66 32

MALLE (BELGIQUE)

6, 7, 8 May 1999

Three days of training and workshops with Theo Peeters and three guests: Phil Christie, director of Sutherland House School and Early Years Centre, Nottingham, Maggie Rigg, Principal of two schools for children with autism and one for children with Asperger Syndrome, Wendy Brown, founder of Helen Allison School, and Broomhayes School for children with autism.

Topics: the implications of autism for teaching and learning; Strategies for dealing with anxiety; Communicating successfully with students with autism and Asperger syndrome; Enabling communication with the young child with autism: an interactive approach; Ways of encouraging responsibility for behaviour; Intervening positively on autism and Asperger Syndrome with specific reference to uninhibited and persistent behaviour patterns; Meeting severely challenging aspects of autism and Asperger Syndrome through education in a variety of mixed settings; Working with siblings; Structure for children, with Asperger Syndrome.

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 E-mail: OPL.CTR.AUTISM@ping.be

GENEVA (SWITZERLAND)

28 June-2 July 1999

Autisme et stratégies éducatives

Formation pratique with Théo Peeters

For more information:

ASPEA
 Marguerite Cachemaille
 23 Hameau de la Fontaine
 CH-1040 Echallens
 Tel.: + 41 21 883 00 83
 Fax: + 41 21 883 00 84

OXFORD (UNITED KINGDOM)

17- 19 September 1999

The search for coherence from the fragments of autism

This Congress will unite those from different fields and perspectives in the world of autism to consider the proliferation of approaches on offer today.

Speakers: A. Bailey, M. Collins, Pr E. Newson, M. Fleisher, H. Watanobe, M. Zappella, E. Danczak, F. Happe.

For more information:

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 St Mawes,
 Aylesbury road
 Princes Risborough,
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 Tel./fax + 44 1844 347351
 E-mail:
 conf@autism-oxford.demon.co.uk

FRANCE

EDI Formation

Edition, Diffusion, Information

- theoretical trainings and educational strategies conducted by C. Tréhin, or C. Durham, or T. Peeters and H. De Clerq
 March, April, June, October, November 99 in the cities of Poitiers, Paris, Angers, le Cannet, Rennes, St Etienne, Strasbourg, Rouen, Bordeaux.
- practical trainings
 February, April, August, October 99
- practical trainings, evaluation and educational individualized programme in Le Cannet
- Evaluations/educational individualized programmes "PEP-R"
 4-8 October 99
- Evaluations/educational individualized programmes "AAPEP"
 22-26 November 99
- Training Collaboration parents/professionals
 October 99 (Paris)
- Training: expressive and receptive Communication
 15-17 November 99 (Paris)

For more information:

EDI Formation
 11-13 Chemin de l'Industrie
 F-06110 Le Cannet
 Canéopole Bat. D, France
 Tel.: + 33 4 93 45 53 18
 Fax: + 33 4 93 69 90 47

PLEASE NOTE

Change of addresses and/or telephone-fax numbers/E-mail:

*Autism Liverpool and Lancashire
Autistic Society*

becomes

*Autisme Initiatives
7 Chesterfield road
Crosby*

*UK - L23 9XL Liverpool
Tél.: + 44 151 330 9534
Fax: + 44 151 330 9536*

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Cover photo: M. Olga Bogdashina, president of the Autism Society of Ukraine and her son, Alyosha.

EUROPEAN ELECTIONS: TOWARDS A EUROPE THAT IS CLOSER TO ITS CITIZENS

Next June, the citizens of the European Union will be electing their representatives in the European Parliament. Autism-Europe is taking this opportunity to raise awareness of the candidates for the European elections on the issue of disability and the expectations of people with complex dependency needs and their families. This campaign is partially funded by the European programme PRINCE. It will allow us to attract the attention of the future European representatives to the perspectives offered by the new European treaty (the Treaty of Amsterdam) to severely disabled European citizens, in order to gain the future MEP's support in the development of policies that really meet the needs of one of the groups most vulnerable to discrimination. A seminar will be organised in Brussels on the 16 April 1999 and will give our member associations and all those interested the opportunity to express their thoughts on the outcome of this campaign at national level and to agree on a follow-up strategy to be implemented after the elections of June 1999.

For example, one of the largest ambitions of today's European Union is the united fight against unemployment. All the member states have been invited in 1998 to present a national action plan on employment. Some of them included a reference to persons with disabilities. None of them however extended this reference to people with complex dependency needs and their families. Yet it is known that the parents and especially the mothers of persons with complex dependency needs are hit much harder by unemployment, because it is often difficult for them to conciliate work and heavy family duties. They form a group that is particularly vulnerable to social exclusion: unemployment, isolation, discrimination and withdrawal are the daily share of families of which a member is severely disabled. Their fate is shared by others: people with small children or a dependent elderly parent. It is essential to adopt strong measures to promote employability of all persons that are confronted with a

higher family burden: measures in terms of flexible working hours (too often only limited to subordinate positions), of gender equality, of longer parental leave when more care is needed (multiple birth, child with disability, dependent elderly parent, etc.), of putting up services that are really adapted to the needs of the persons who have to be cared for (infants, persons with complex dependency needs, elderly people, etc) and their families.

The European Commission has also decided to look into the social security problem and has recently proposed a new regulation to the Council of ministers of the European Union to facilitate the life of Europeans moving around in the Union and to guarantee their rights in terms of social security. At this point, still a long road has to be travelled to recognise the needs and the rights of disabled persons.

Finally, the human rights issue is at the core of the concerns of the European decision-makers and all agree in saying that one has to combat the discrimination suffered in particular by disabled people. With the enlargement of the European Union to new countries, it is our task to ensure that the prerequisites regarding human rights will include an adequate reference to the rights of persons with disabilities, in particular persons with complex dependency needs because the majority of them will pass their entire life in sordid institutions, forgotten by everybody. It is up to us now to tell them concretely how the European Union can help ensure real equality of opportunities for everyone.

More and more decisions affecting our life and that of our children are taken at European level. This is why it is important to grasp the opportunity of the European elections to participate in the construction of a Europe that is closer to its citizens by sharing our concerns and legitimate expectations with the candidates.

*Gilbert Huyberechts
President*

AUTISM SOCIETY OF UKRAINE

FROM DESPAIR TO HOPE

History: state of the problem of autism in Ukraine. Establishment of the Autism Society of Ukraine

Let me introduce myself. I am a professor of Teachers' Training in an Institute in Gorlovka, (Ukraine). And I am the mother of an autistic son (Alyosha, born in 1988). He was born without problem and developed normally (at least I thought he did) until the age of two. Then I understood that something was wrong with my boy because he stopped talking and seemed, to live in his own world. I tried to do my best to find the best doctors to examine him and rushed from one specialist to another one. But they only shrugged their shoulders, they didn't know what was wrong with my son as he looked normal. Between two and three years, his behaviour changed completely and became very challenging: he was screaming a lot, doing tantrums, etc. And then our doctors made a diagnosis: he was lacking speech and was severely mentally retarded. I couldn't agree with this diagnosis. I had the feeling that my son was not mentally retarded, but I could not prove it.

The first time I heard of autism was in 1993 when I found by chance a book called "Children with Autism. A Parents' Guide" edited by M.D. Powers. While I was reading this book I had the feeling that it was written for me and my son. The problem was that nobody in Gorlovka (and, probably, very few people in Ukraine) had heard of autism at that time. The Kindergarten refused to take my son because of his behaviour and his lack of speech. You can imagine what I felt. However, I couldn't give up because I knew that nobody would be able to help my son except me. Now I knew the enemy I had to fight.

I was sure that my son wasn't the only child with autism in Gorlovka, in Ukraine. So my next step was to find other parents with autistic children in this region, because the only way to support our children was to join our efforts to help them find their place in this world. I send an article to our local newspaper, describing my son and my ideas on how we could help such

children. Within one week sixteen parents contacted me. (our society includes more than 150 members now) They recognized their own children in the description of my boy. They had lost the hope to help their children who were not accepted in any kindergartens, or schools. The parents were advised to institutionalize them what they refused and then the children stayed at home.

I should explain the situation in Ukraine regarding children with special needs. These children are assessed by a panel of "experts" for 5-10 minutes. They are told to achieve some tasks. If the child does not finish the tasks he receives the diagnosis of learning disability and is offered a place in an institution. If the parents - whose wishes are not taken into account - refuse, the child is forgotten by the Education Department (out of sight, out of mind). The parents do not receive any kind of professional help and have to keep their child at home.

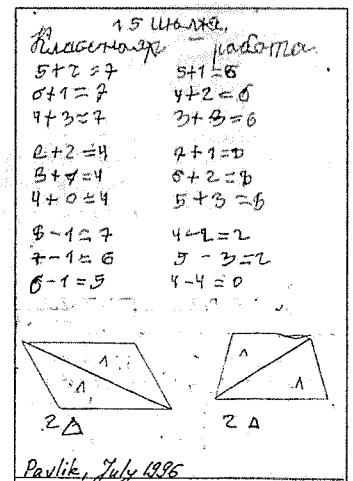
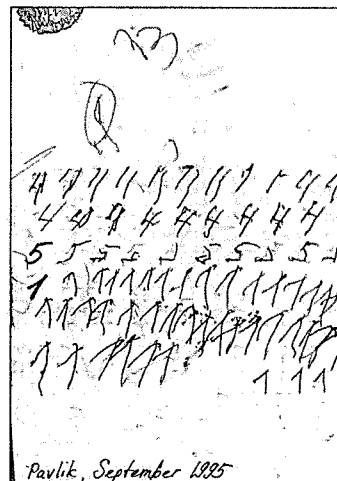
To give you an idea of the misunderstanding of the problem by our chief town and regional "specialists" who are the authorities entitled to determine the future of the children with special needs, I will quote some of them:

Chief Donetsk region psychiatrist: "If your child is autistic, he is not allowed to attend any school and should be kept in isolation from other children because he is dangerous".

Chief Gorlovka speech therapist (when the mother of a non-verbal child, aged 7, asked what to do to help her child communicate): "Do you really think that a speech therapist should work with him? he doesn't talk. How can we teach him to talk? Come to us, when he starts talking, then we'll work with him". (I understand it as: "Let him learn how to swim and we'll pour water in the swimming-pool".)

Some other specialists consider autism to be synonym of "childhood schizophrenia" or "mental retardation" and they declare that these children are uneducable.

The process of assessment itself is very humiliating for the parents and stressful for the child. Our "specialists" - members of the assessment panel - don't take into account the most elementary thing: the children have spent their six or seven first years at home, within four walls, surrounded by two or three very close persons. And all of a sudden these children were placed into an unfamiliar room with



Pavlik's progress in one year.



Autism Society of Ukraine, Storm House Day School, Gorlovka, February 1997

five or six unknown persons, who asked them all kinds of questions. It was also very difficult for the parents to explain the autism of their child (to tell the truth, our "specialists" didn't recognize autism). For example, a 6-year-old boy who could already read (though his: speech was very limited) was told by a member of the panel to assemble a pyramid, a task he coped with when he was two years. Naturally, the boy didn't pay any attention to it. The members of the board exchanged significant glances. So, what was their conclusion? Well, nobody will tell the parents the diagnosis given to their child) - never in their lives! Finally, the majority of the children assessed by the panel were offered a place in institutions without any chance to receive education or training.

The only document the parents received after several months of waiting was an official letter from the Donetsk Education Department in which it was written that there were no children with autism in Donetsk region, except one - Alyosha Bogdashin who has the syndrome of autism associated with "the main disease - schizophrenia".

In 1995, knowledge and resources regarding autism were almost non-existent. And our "experts" recognized that only one child in Donetsk region had autism on a population of 5 millions people (in Gorlovka, there are about 340.000 people) and this child was my son. (it was not because they admitted he had autism, but just to get rid of me) It was a very convenient position: no autism - no problems related.

I must stress that the economic conditions in Ukraine are very bad nowadays. The main objective for everybody is to survive. Teachers, doctors, miners have not been paid for months. Kindergartens are closing because there is no more money to buy food for the children.

We are demanding specific treatment for our children when there is a general lack of resources available for all public services. But in spite of these difficulties we do not want to lose our children.

We, parents of children with autism, decided to help our children ourselves, and in July 1994 we founded the first Autism Society in Ukraine "From Despair to Hope". The Society is legally registered and we have an official Status, and have appointed a voluntary President.

The main aims of the Society at this initial stage are:

- to promote awareness of autism and draw attention of the public to the problems of children with autism;
- to find out how many children with autism are living in Donetsk region (Eastern Ukraine) and then spread our activities to the whole Ukraine;
- to be a contact point for other organisations liable to help children with autism;
- to provide a centre for education for children with autism;
- to provide support for the families.

We started to establish links with Autism Societies and Autism Research Institutes in the USA, in Great Britain and in other countries. As the main

problem in Ukraine was the lack of information on autism, on treatments and on specific education for children with autism, we translated the materials received from these organisations into Russian and distributed this information among the professionals and parents of children with autism. With the help of our English friends, we published a leaflet "What Is Autism?" in order to promote awareness on autism and draw the attention of the public on problems and needs of children with autism.

In order to be part of the European movement for the rights of people with autism, the Autism Society of Ukraine applied to the European Association Autism-Europe in April 1996. The application was sponsored by the NAS (UK) and the Irish Society for Autism. The application was approved and confirmed by the General Assembly of Autism-Europe on November 23, 1996, and now the Autism Society of Ukraine is an associated member of the International Association Autism-Europe.

Since that time our Society has translated the most important documents concerning people with autism (Charter for Persons with Autism, The European Parliament Written Declaration on The Rights Of People With Autism) from English into Russian and other materials dealing with diagnosis and treatment of autism.

I was convinced that specialized education and appropriate care could be very beneficial for children with autism in Ukraine. Our next objective was to create a school for them.

We gathered all the necessary information, worked out educational programmes for children with autism, and met responsables of the organisation whose duty is to provide education for all children in town - the Education Department.

However, we were too naive to believe that this Department would be pleased to know the latest achievements in the field related to their work. We did our very best to persuade the bureaucrats of the Education Department that it was urgent to establish one experi-

portrait

PORTRAIT

mental group at least in one of the schools. The sooner these children would be taught, the greater the opportunity would be for them to have a better future. We hoped that our "educationalists" would solve the problem, but...

Having got all necessary materials, projects, programmes, etc. the head of the town education department and the head of the institutions for children with special needs promised to study this question. Since September 1994 this question has been being studied. No results.

The parents of children with autism, driven to despair, decided to start a school for their children themselves.

Opening of the school for children with autism in Gorlovka

On 10 March, 1995 we founded the first experimental group for four children with autism, aged 6-9, without any permission from our local authorities as we couldn't wait any longer for their decision. A school allowed us to use two small rooms which were empty. The parents brought some materials and the classes could start. The response, of the Education Department was immediate: they wrote official letters to the Institute where I worked demanding that I stopped, because I had no right to teach these children and my activities were dangerous! This is a paradox I cannot explain: instead of welcoming this project our "respected" bureaucrats put obstacles in our way. They themselves did not do anything to help the children, and they did not want us to help them. The future of our children was at stake. Finally, we found help from our friends in Barnsley, England (the twin-town of Gorlovka).

The Barnsley Council's Public Relations Department put us in touch with the National Autistic Society and on the 1st of September 1995, we opened the small school for four children with autism in Gorlovka. We have saved a little of money each month to employ a teacher. The class of our "unteachable" children has been named "Storm Class!" in honour of the support given by Storm House School for children with autism, England.

In November 1995, we created another group for three more children, aged 4-7, nonverbal, and a month later - for two more children. (Now we have 11 children with autism in our small school.)

Our aim is to create more classes for children with autism in Gorlovka and in other towns of Ukraine.

Our children are doing very well at school. These children who are considered to be "unteachable" have improved their behaviour and have shown considerable progress in learning academic knowledge. You can see the results of our work by comparing exercise-books on Russian and Mathematics of the same children at the beginning of the school year and at the end of it (in 10 months).

Unfortunately, these classes are not recognized by our educational authorities, as these children are still considered to be unteachable and we have neither financial nor moral support from the State. But our children are happy now, they enjoy being together and play games at school.

A movement for a better future for disabled children has been initiated by parents of disabled children in other towns of Ukraine.

Our links

In October 1995 Mr Kit Howe, Deputy Principal of Storm house school for children with autism in England visited Gorlovka to examine the children and he offered support to our Society. Mr Kit Howe accepted the honorary position of Vice President of the Autism Society of Ukraine "From Despair to Hope". Mr Kit How saw eleven children he has confirmed to be affected by the autistic spectrum. He has informed educationalists from the Donetsk region, medical officers and neurologists of this fact and put the stress on the important role they could play in elaboration diagnosis and providing resources for children with autism in the whole Ukraine.

I am very grateful to Mr Kit Howe and the NAS for this historical visit. We view this great event as the new great October non-socialist revolution in this country.

Mr Howe invited me, my 7-year-old son and the teacher of Storm Class to visit Storm House School for 3 weeks in February 1996 in order to learn about treatments for children with autism in England. It was a valuable experience for us.

We thoroughly enjoyed the experience of visiting Storm House School where we observed 12 classes of children

with autism. We realised that our friends in Barnsley were not indifferent to the future of our children. We are very grateful to all our English friends who have given us so much support in our fight. We are especially grateful to Androa, Gillian Roberts, Kit Howe and Colin Heath for the extra care and time that they have given to ensure fully enjoyable and beneficial time in England.

During our stay in England, we also visited the Adult Centre for people with autism - Raby Hall, and we met Donna Williams. I greatly admire this woman who has overcome the problem of autism and created a life for herself despite her disability. I read numerous articles and books on autism but I have never been so inspired or relieved by the books written by Donna Williams "Nobody Nowhere", "Somebody Somewhere" and "Autism - An Inside-Out Approach". Her books contain valuable authentic information of what it is like to be a person with autism and give us some ideas of the kind of difficulties that are faced by people with autism. Her books and activities help to bridge a vast gap between the autistic and non-autistic world.

Our personal meeting with Donna Williams was unforgettable. I was very much impressed by the fact that she understood my son in spite of different languages they spoke. She gave me explanations of some of his odd behaviours and valuable advice to help him to improve them. I came back home with great enthusiasm and desire to help other children with the same problem. But again the first thing we are to do is to break the wall of ignorance and "shut-mindedness" of Ukrainian bureaucrats.

Current activities of the Autism Society of Ukraine

On 6th-7th December 1996 the Autism Society of Ukraine organized the first training seminar for doctors, teachers and parents of children with autism "Autism: Yesterday, Today, Tomorrow", to mark the Autism Awareness week. Different questions were discussed: the definition of autism, history of the problem, diagnosis of autism, treatment, etc. The majority of those present were parents who were happy to learn more about autism and related disorders, in order to better understand their children and their needs. Unfortunately, the officials of Donetsk Region and Gorlovka Education Department ignored this seminar and did not come although they had been invited. They

still thought that autism was an invention of the parents and that they knew everything they needed and did not need more information.

On 5-7 May, 1997 the Autism Society of Ukraine in collaboration with Donetsk region Department of Family and Youth held the 1st International Autism conference in Ukraine "Autism Doesn't Know Any Boundaries".

Mr Kit Howe, Deputy Principal of Storm House School and Mrs Gillian Roberts, Deputy Principal of Priory School for children with autism, in England, took part in this conference. They told the audience about assistance and support of people with autism in England, main characteristics of autism and ways of improving the work. They appreciated the work done with the children with autism in Gorlovka Storm Classes. Other practitioners and scientists of the Donetsk Region participated in this conference. The contributions have been compiled, published and distributed throughout Ukraine.

We have established cooperation with the social services of Donetsk region, and together we are trying to found a centre for diagnosis, treatment and education of children with autism and related disorders. Fortunately, there are some open-minded social workers in Ukraine who support us. The main obstacle on our way now is the "Soviet mentality" of our public authorities that must now think in terms of individuals and not in terms of statistics.

On 6 July 1998 the Autism Society of Ukraine "From Despair to Hope" celebrated its 4th anniversary. We are just at the beginning of the road which many countries passed 30-40 years ago. We are following the same way and we can use achievements and experience of the others that will help us move quicker. We have already covered a long path. Autism is now diagnosed in Ukraine, more and more people are aware of autism and the need to work with children with autism. And though, sometimes we were thrown back - from hope to despair, we are optimistic: we are following the right way and we will find strength to help our children and keep on going forward -From Despair to Hope.

*Prof. Olga Bogdashina
President of the Autism Society of
Ukraine "From Despair to Hope"*

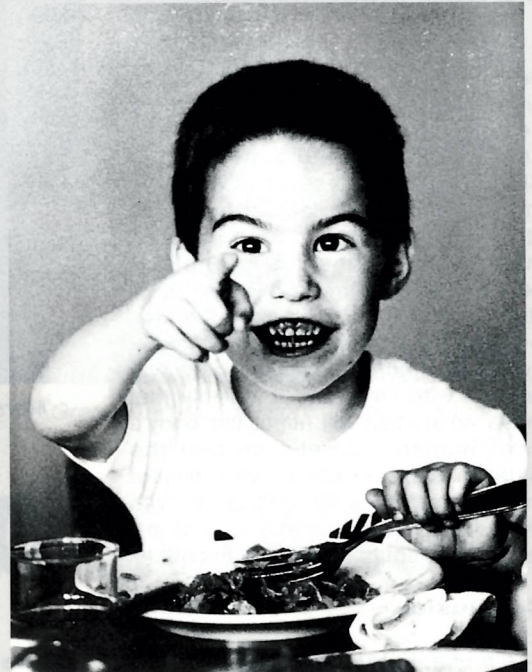
SECRETIN AND AUTISM

Much publicity has recently been given to the possible use of infusions of secretin in the treatment of autism. There are very few solid facts on its use but very large number of anecdotal reports from parents, physicians and one or two people with autism. The position is changing rapidly but, at the moment, is as follows.

Secretin is a hormone which has been known for many years. Chemically speaking, it is a peptide and consists of a chain of 27 amino-acids. It has a number of actions in the body and it is not clear which or how many of these are of relevance to any amelioration of the symptoms of autism.

- a) It stimulates the pancreas to produce a range of products. These include bicarbonate to neutralise the acid coming from the stomach, peptidase enzymes which will break down the peptides from the intestines (which many believe are causation of the problem) and a number of other specific enzymes.
- b) It has a stimulus effect on certain elements of its immune system which are known to be sub-optimal in people with autism.
- c) Like many substances active in the intestines and immune system, it will have direct effects in the brain and it could be that these are of relevance.

Secretin has, for many years, been derived from pig intestines and is comparatively impure. It has been employed even though it had no product licence, to test pancreatic functions and any beneficial effects in autism as subsequent increase in demand, were not anticipated by the manufactures (Ferrings of Sweden). Unfortunately on account of lack of demand, the company ceased production in the summer so supplies are



very limited indeed and effectively non-existent in Europe.

Does it work ?

There are at least two clinical trials being performed "officially" in the USA, but a number of physicians are performing their own, less controlled studies. Additionally, many hundreds of parents have been experimenting and discussing their results on the Internet.

There can be little doubt that some children have made progress which approaches the astonishing, whereas others have shown no benefits whatever, and there are all studies in between. So far no characteristics have

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SECRETIN AND AUTISM (continuation)

been identified which are predictive of success. Improvements in sociability, language and bowel functions are most commonly reported. The only real drawback seems to be a hyperactivity which persists for four or five days after infusion and a very transient increase in temperature. The drug is currently administered by intravenous infusions and the benefits appear to last for 3 or 5 weeks. Some parents are experimenting with oral drugs or transdermal applications but results are even more equivocal and there could be additional problems as well as benefits.

Are there problems ?

It is probably true that, as the manufacturers state, there are no known side-effects but, this is probably because secretin has never been employed as a regular medication. Side-effects always occur with any medications. There are at least two other potential problems and vigilance must be maintained. Secretin has been obtained from the pig and so is slightly different to the human form (as with insulin). It is inevitable that antidotes to this "foreign" peptide will emerge with time, and it is likely that these antibodies will affect the body's own "human" secretin so that the situation is exacerbated. Even, without this problem, it is likely that, as with most forms of medications, any effectiveness could diminish with time.

Conclusion

It is probably true that secretin does help to ameliorate the symptoms of autism in a proportion people with autism (unofficial estimates vary between 40 and 70 %). The situation is, on account of lack of data and lack of secretin, very much one of "wait and see". More information is on the way. The situation is being watched by the regulatory authorities with a view to rapid assessment for approval should efficacy and safety be demonstrated. (It is likely that biotechnological technique will enable the production of human insulin within a few months).

Even if, secretin is not shown to have a use as a medication, the information derived so far does initiate some areas which could be profitably explored.

*Paul Shattock,
University of Sunderland, UK*



Merry Barua (India), Vice President Asia

On November 21, 1998 the "World Autism Organisation" (WAO) was officially launched during a ceremony held in the hemicycle of the European Parliament in Luxembourg in the presence of Her Royal Highness the Grand-Duchess Josephine-Charlotte.

OFFICIAL LAUNCH OF W

The initiative for WAO was taken by Autism-Europe, starting from a suggestion by Hans Wulffsberg from Denmark. This idea came from two observations:

1. So far, the World Health Organisation has no office for autism nor publications on autism, UNESCO has no education program for autism, etc. WAO will advocate for such worldwide endeavour.
2. The majority of autistic people reside in countries where services are either very weak or in-existent.

So one reason for creating the "World Autism Organisation" is to get recognition from such organisations as WHO, UNESCO and United Nations and promote actions in favor of autistic people through them.

The other reason to create this new organisation will be to promote support to autistic people in countries where it is inadequate. This will be done through information programs and professional training.

The first General Assembly of WAO will be organised in the year 2000, coupled with the International Autism-Europe Congress, "Making our Dream Reality" in Glasgow, May 19-21.

By that time we would like to have a maximum of countries from all continents represented. To that effect, please feel free to distribute this information to Parent or Self Advocate societies or to individual people whom you feel might want to join this new organisation.

The organisation that was announced on November 21 is the framework for starting our worldwide support group.



Gilbert Huyberechts, President Autism-Europe, welcomes Her Royal Highness the Grand-Duchess Joséphine-Charlotte in the European Parliament in Luxembourg.

WORLD AUTISM ORGANISATION (WAO)

To that effect, on Sunday November 22, we proceeded to the formation of a first "Interim" Council of Administration in charge of setting up the future organization structure and functioning rules.

The Council was elected by the delegates attending the founding meeting. The interim Council then elected the following delegates to the Executive Committee:

- President: Pat Matthews (Ireland)
- Vice President Africa: Willelm Kabemba Lutumba (Congo)
- Vice President Asia (Indian continent): Merry Barua (India)
- Vice President Asia (Far East): Conchita Rragio (Philippines)
- Vice President South America: Isabel Bayonas (Spain)
- Vice President Europe: Christos Alexiou (Greece)

- Secretary General: Paul Trehin (France)
- Treasurer: Joan Roca i Mirales (Spain)

The other members of the Council are:

- Hans Wulffsberg (Denmark)
- Evelyne Soyez (France)
- Kees Helmstrijd (Netherlands)
- Rita Thomassin (France)

The statutes presented on November 21 are by no means set in stone. A slight amendment regarding individual membership was adopted on Sunday 22 November by the founding members present in Luxembourg and it is more than likely that during the period between now and May 2000, the statutes will need to be revised in order to fit the needs and preferences of autistic people and their parents.

The Interim council has been requested to collect comments throughout the world and make proposals to the first General Assembly in May 2000.

If you wish to have the latest version of the statutes adopted in Luxembourg, please let me know (trehin@aol.com) or contact World Autism Organisation c/o Autism-Europe via e-mail (autisme.europe@arcadis.be).

*Paul Trehin,
WAO Secretary General*

CAMPAIGN AGAINST PROHIBITED PROCEDURES

The Irish Society for Autism launched a campaign in partnership with APPDA (P), CAP (UK) and Autisme France (F) to outlaw certain practices which are employed in the treatment of children and adults with autism.

Sometimes, cruel, humiliating and degrading actions are performed out of ignorance, carelessness or stupidity and because the perpetrator believes that "there is no alternative". Sometimes, such cruelty is deliberately vicious, shows a callous disregard for fellow human beings and would be regarded as a criminal act if performed on a dog.

In spite of assertions to the contrary, we know that such treatments are unnecessary. We also know that they achieve nothing except to leave vulnerable people dehumanised, very confused and permanently terrified.

Unfortunately, we know that without the backing of legislation that is vigorously enforced, attitudes and priorities will not change. This initiative on "Prohibited Procedures" is designed to promote legislation that must act.

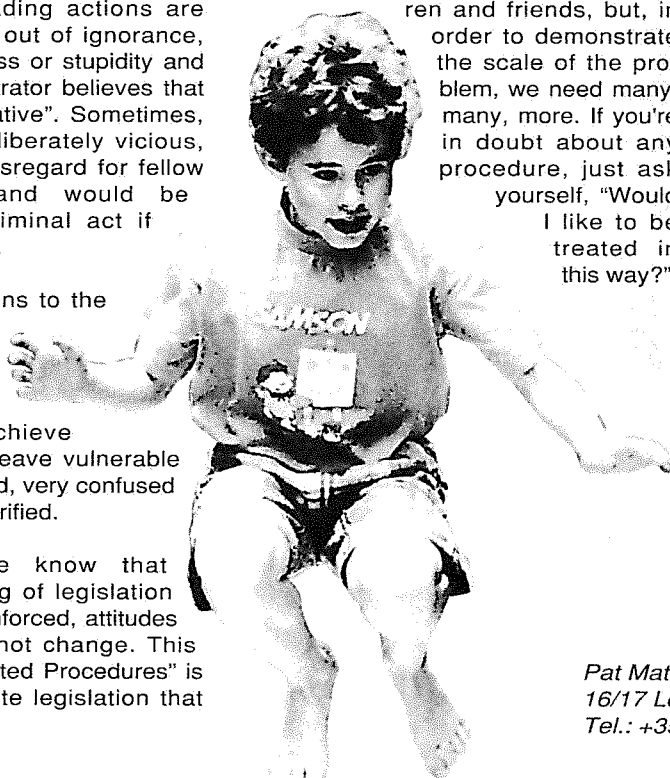
What constitutes abuse?

Abuse can take many forms. It could be deliberate starvation or the administration of noxious foods; it could be the deliberate infliction of pain, a long period of restraint in confined spaces or being tied up. It could involve the use of mind-numbing drugs or the denial of appropriate medical treatment. In another context, these acts would be seen as torture. Sometimes the abuse is less blatant; it could involve intimidation, threats or the denial of any form of choice. As one therapist explained "What does it matter? They can't speak anyway".

We have for the past year been attempting to accumulate evidence with which to back up our claims. We have many specific instances of persistent violence and cruelty towards our children and friends, but, in

order to demonstrate the scale of the problem, we need many, many, more. If you're in doubt about any procedure, just ask yourself, "Would

I like to be treated in this way?"



If the answer is "no", the procedure must be changed.

Reporting abuse

Our main problem is the refusal of parents to report such incidents; of course, all instances must be authentic and supportable but will be treated anonymously so as to make identification of the perpetrators or the services impossible unless already in the public domain.

So often, we hear of children, real people, who are tied up all day, whose therapy consists of someone sitting on them all day; whose teeth have been removed to prevent biting; who have been in solitary confinement for weeks yet parents and carers are scared to report to us.

Some parents actually believe that such treatments are appropriate because the professionals (who also believe it) tell them so. Desperate parents believe or have been told that the children will be ejected from a service if they report abuse. Agreed, the decision to report is difficult, but unless legislators are convinced that such cruelty is widespread and that safer, more effective and change options exist, they will not act to prevent this torture of people with autism or any form of disability.

If you are aware of specific incident or practices; if you have newspaper cuttings, court reports, personal experiences or concerns, you should contact us immediately. Do it now!

Anonymity would be preserved without your express permission.

*Pat Matthews, Irish Society for Autism,
16/17 Lower O'Connell Street, IRL - 1 Dublin,
Tel.: +353.1.874.46.84, Fax: +353.1.874.42.24*

Revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), World Health Organisation

The work of Autism-Europe in the revision of the International Classification of Impairments, Disabilities and Handicaps to ensure that the revised classification will meet the needs of people with autism has progressed. A first proposal prepared by Dr Fuentes of Gautena was welcomed by WHO. The second round of worldwide consultation is now finished, a special Autism-Europe questionnaire had been prepared by Donata Vivanti and

Joaquín Fuentes for that purpose. Our co-ordinated response reached WHO end of January 1999. A new round of worldwide consultation will start in April 1999. If you are interested in participating in these field trials on ICIDH-2 Beta 2 version, please contact Autism-Europe (please note that you need to have access to Internet as the WHO bulky documents are only available on line).

FINAL SEMINAR OF THE EUROPEAN EXCHANGE PROGRAMME

“Optimilisation of residential services and promotion of employment for adults with severe autism” organised by Fondation Autisme Luxembourg

On 19 and 20 November 1998, the final seminar of the European exchange programme took place in the hemicycle of the European Parliament before a large public and numerous personalities. This seminar was organised by the Fondation Autisme Luxembourg.

This exchange programme consisted in four visits in very innovative residences: Mistral (Belgium), Dunfirth Communities (Ireland), GAUTENA (Spain), Abri Montagnard (France). The visits were aimed at parents of adults with autism from five co-partner associations: Fondation Autisme Luxembourg, Autisme-Espoir (Metz, France), Hilfe für das Autistische Kind Saar (Germany), Angsa-Lombardia (Italy) and Aide aux Adultes Autistes (Belgium), who are faced with problems of inappropriate care of their adults with autism. Actually, in this region, there is no specific structure for adults with severe autism. These adults are obliged to stay in their family with the problems related to the physical and moral harassment, with their parents growing old. Some are placed in psychiatric institutions or in centres for mentally disabled persons without appropriate care of the specific disability that autism is.

The main aim of these visits was to encourage exchange of experiences, of knowledge, of techniques to enable parents to determine guidelines in order to improve the residential services for persons with autism and promote their employment.

This programme ended with a final seminar in Luxembourg. The directors of

the visited centres and specialists in the field of autism presented their experience and their research in front of a crowd of a hundred parents wishing to benefit from the conclusions of the European programme:

Nuala and Pat Matthews presented Dunfirth Communities (Ireland); Serge Thomas, brother of a young woman with autism, spoke in a very personal way of his experience; Irène Knodt - Lenfant presented the services of Mistral near Liège in Belgium she has founded; Liz Scott, mother and teacher in Luxembourg presented her views on the role of the family in the transition to adulthood; Flo Longhorn, expert in specialised education in Luxembourg, presented the fundamental rights of adults with autism: liberty, dignity and equality; Ramón Barinaga, director of GAUTENA in Spain, presented their services for persons with autism; Paul Shattock, from Sunderland University (UK) spoke about the complementary use of medicines in autism; Dr Joaquín Fuentes, child and adolescent psychiatrist in GAUTENA, explained the Pharmautism project; Paulette Foueilis and Rita Thomassin, both mothers and responsables of Abri Montagnard in France presented in a very vivid way their residences for adults with autism; Dr Jean-Marie Spautz, director and practitioner in neuropsychiatric hospital of Ettelbruck (L) outlined the situation of persons with autism in neuropsychiatric hospital in Luxembourg; Claude Schmit, vice president of Fondation Autisme Luxembourg presented a residential project for adults with autism in Luxembourg and Gilbert Huyberechts, president of Fondation Autisme Luxembourg concluded this seminar.

The report of the visits and the final seminar has been published and is available at Autism-Europe secretariat or upon request at Fondation Autisme Luxembourg, c/o Claude Schmit, 36c Cité Patton, L- 9068 Ettelbruck.

AUTISM-EUROPE SETS UP A EUROPEAN DOCUMENTATION CENTRE

In its documentation centre, Autism-Europe has collected journals, conference reports, clippings, brochures from its member organisations, books and information coming from the Internet. The database we are setting up is searchable by subject. A list of the used keywords (in English) is available. It is possible to search by keywords related with:

- autism in general
- therapies and methods
- education and phases in life
- organisations, members and countries
- research
- practical training
- addresses, websites, services
- human rights
- pharmacology, medical, genetics, ...
- European Union

In answer to the appeal we have launched in October 1998, many member organisations have sent us a list of their publications. When all the titles will be entered in the database, it will be possible to direct searchers to the member organisation who has the information available. We still welcome your contributions to the documentation centre; please notify us about your publications, or, why not, your website!

Our Web site is regularly updated. We invite you to visit it once in a while and send us your comments. This helps us serve you better.

*Hilde Lambeir,
documentation officer*

PRE-PROFESSIONAL APPRENTICESHIP

"The most beautiful day of my life was when I was able to go to work," said Dick Donovan, an adult with autism, during a congress.

Because persons with autism have problems with behaviour, with communication, with socialisation, and often also have a learning disability, it is very important to present to them a pre-professional apprenticeship that is adapted to their abilities, with tasks that are concrete, clear and visible, with work that is clear and easy to understand.

These youngsters can be very skilful when the necessary hand movements are in their reach. The child with autism is only distressed when a task exceeds his capacities. Every failure triggers a refusal and relational difficulties.

The educator has to establish a programme taking into account:

- The environment of the proposed task
- The analysis of the task in order not to ask too much at the same time (pedagogical progress)
- The development of a list of competencies
- Determination of the objectives
- Control and adaptation of the objectives, if necessary

Many different techniques can be taught. Up until now, our students have been practising administrative tasks among which:

- Pasting a label, pasting a stamp
- Folding an A4 sheet into four
- Folding an A4 sheet into three
- Folding a newspaper in two
- Putting a leaflet into an envelope
- Stapling a magazine
- Stapling a pile of A4 sheets
- Putting 4 different cardboard pieces in an envelope
- Putting 4 Christmas cards, 4 inserts and 4 envelopes in a cellophane bag to be glued and labelled

At first the techniques are being taught individually, with an adult staying next

to the student and providing a great deal of manual support. The amount of support decreases over time when the student progresses and acquires new abilities.

When you don't know how to tackle an activity, keep asking yourself the same question: "Is it autism that prevents him/her from doing this activity or it is I who didn't find the right way or time or will to teach him what is missing?"

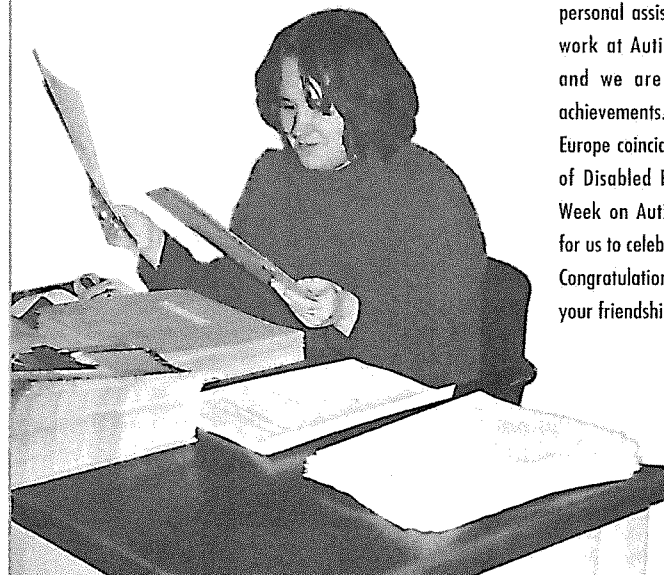
Our students undertake different kinds of work, with difficulties, but with love and in a relaxed way.

After seven years of experience, I must conclude that the preparation to future employment cannot start too early. For a person with autism, the route to social integration and semi-professional integration is a long way.

*Elisabeth Schattens
Teacher in La Clairière, Brussels (B)*

YOUNG STAGIAIRE WITH AUTISM JOINS AUTISM- EUROPE'S STAFF

Yolande Ullens, a young 18-year-old woman with autism, joined Autism-Europe's staff as a stagiaire last December 3rd. Yolande, who attends La Clairière special school in Brussels (see LINK 24), comes every Thursday morning to help our staff with various administrative tasks such as preparing letters for mailing. After a few weeks preparation, Yolande is now able to work on her own and join the rest of the staff for tea breaks without the support of a personal assistant. Yolande enjoys her work at Autism-Europe tremendously and we are all very proud of her achievements. Her first day at Autism-Europe coincided with the European Day of Disabled People and the European Week on Autism: a very symbolic way for us to celebrate these two events. Congratulations Yolande and thanks for your friendship and bright smiles!



General Assembly of Autism-Europe, 21 November 1998, Luxembourg

The General Assembly of Autism-Europe met on 21st November 1998 in the hemicycle of the European Parliament in Luxembourg and followed the final seminar of the European exchange programme organised by Fondation Autisme Luxembourg.

In addition to the representatives of the member associations and individual members were also present the founder members of the World Autism Organisation whose statutes were signed at the end of this General Assembly.

According to the statutes, part of the Council of Administration have been (re)elected and the new CA is now composed of the following members: Christos Alexiou, GSPAP (Greece), Isabel Bayonas de Ibarra, APNA-Madrid (E), Ramon Barinaga, GAUTENA (E), Peter Borg Neal, NAS (UK), Marc Cautreels, VVA (B), Janet Corcoran (NAS) (UK), Marie-Antoinette Dunant, ASPEA (CH), Freddy Hanot, APEPA (B), Carlo Hanau, APRI (I), Kees Helmstrijd, NVA (NL), Waldtraut Judt, HAK (D), René Lambeir, VVA (B), Gloria Laxer, Autisme Bourbonnais, (F), A. Lester, SSAC (UK), Sergio Martone ANGSA (I), Joan Roca i Miralles, APAFACC (E), James Murray, Autism Initiatives (former Liverpool and Lancashire Autistic Society) (UK), Claude Schmit, Fondation Autisme-Luxembourg (L), Antonia Serra de Paz, Mas Casadevall (E), Evelynne Soyey (Apecade (F), Miriam Tomassoni Poggiolini, APAMA (I), Jan Toessebro, LFA, Norvège, Nicole Toureille, Pro Aid Autisme (F), Rita Thomassin, SESAME-AUTISME (F), Paul Tréhin, UNAPEI (F), Marie-Claude Urban, Autisme-France (F).

The Executive Committee includes: Gilbert Huyberechts, President (L), Isabel Cottinelli-Telmo, Vice-President, APPDA, (P), Pat Matthews, Vice-President, ISA (IRL), Paul Shattock, Secretary, CAP (UK), Rita Thomassin, Sésame Autisme (F), Donata Vivanti, ordinary member, Autismo Italia Onlus (I), Bjarne Christensen, Treasurer (DK).

Autism-Europe statutes were amended to be in accordance with the eligibility criteria of the European Disability Forum (EDF). These amendements ensure the representativity of persons with autism and theirs parents within the governing bodies of the association. (The new statutes are available upon request at Autism-Europe secretariat).

The General Assembly approved the applications for membership of the following new associations.

Effective members:

Autism Services East (IRL) (sponsored by I.S.A.)
Fondation Autisme Luxembourg (L) (sponsored by Gautena; Angsa-Lombardia)
Cyprus Association for Autistic Persons (Cyprus) (sponsored by GSPAP):
Autismo Italia Onlus (I) (sponsored by Angsa Lombardia)
Association des Parents et Amis d'Enfants Inadaptés de Casablanca, Maroc (sponsored by ASPEA and Autisme Loire)

Associated members:

Association for the Care of Autistic Persons (Croatia) (sponsored by SHPAC-Croatia; NAS)
Association Alizee & Axel pour les enfants autistes (F) (sponsored by Autisme-France; Autisme-Ile de France)
Asociacion de Padres de Ninos Autistas de Granada (E) (sponsored by APAFACC; Asociacion Nuevo Horizonte)
Association Autisme et Troubles Apparentés - Education 69 (F) (sponsored by Autisme France; Autisme Auvergne)

Autism-Europe is now grouping 71 associations in 29 countries (see list at the end of this edition).

EUROPEAN AWARENESS CAMPAIGN IN THE FRAMEWORK OF THE EUROPEAN ELECTIONS

Thanks to the support of the European PRINCE programme, Autism-Europe is now launching a European campaign to raise awareness on the perspectives the new Amsterdam Treaty offers to severely disabled people and their families. This campaign is twofold: its first objective is to raise awareness among the candidates to the European Parliament elections on the needs of families of severely disabled people; the second objective is to empower family members and associations to enable them to participate pro-actively in the construction a more social Europe. A final seminar will be held in Brussels on 16 April 1999 in the presence of representatives of member associations, members of the European Parliament and candidates to the European election.

For more information, please contact Autism-Europe

COURRIER
COURRIER

LETTER FROM NIGER

In spite of various difficulties, we try as much as possible to take care of the children...and that is not easy because to the problems of autism are also associated those of malnutrition and we are short of almost everything. We would be very grateful to receive educational material for the classes we have created. Thanks a lot in advance to contact us.

*Yauli Linankoy
Association Espoir pour
l'Autisme au Niger
E-mail : istccfn@intnet.ne*

NEWS FROM SPAIN

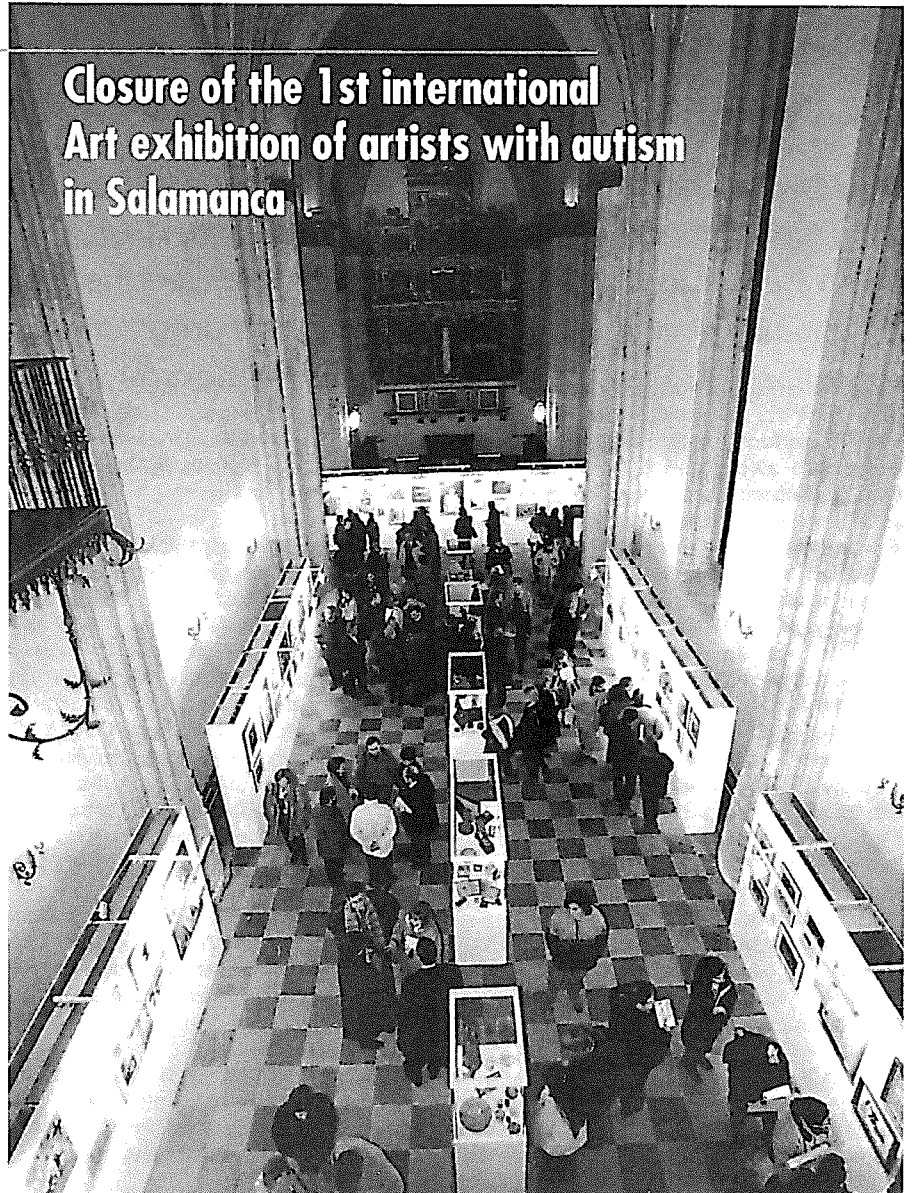
We were very pleased that the 1st international Art exhibition of artists with autism met such a great success after Burgos in all European countries where it was presented: in Hungary, Portugal, the United-Kingdom, Ireland, Belgium and Switzerland. Each time, the visitors admired the quality of the works and the talent of the young artists. At the same time, conferences and other events related to autism were organised to raise awareness on the artist's efforts and personality.

We think that the aims of this 1st International Art Exhibition of artists with autism (presenting the problem of autism, proposing a positive image of the people with autism and showing their artistic ability throughout Europe) have been widely achieved. We would like to thank all the persons and all the associations which committed themselves voluntarily in the project and contributed to its success.

Autismo-Burgos Association organised the closure of the 1st international Art exhibition of artists with autism in Salamanca (Spain), the next European capital of Culture. The closure coincided with the global week on autism (from 30 November to 6 December 1998). The University of Salamanca, one of the oldest university in Europe, allowed us to use the Fonseca Palace Chapel as exhibition hall.



Closure of the 1st international Art exhibition of artists with autism in Salamanca



This event was a real success and a lot of people and associations working in the field of autism came from all around Spain and Europe to participate in this closing exhibition. Mrs Michele Parks, of the Scottish Society for Autism was also present.

Autismo Burgos and SSAC have begun to organise "Artism 2000", the title given to the 2nd International Exhibition of artists with autism which will be held in Glasgow during the International Congress in May 2000.

We were very pleased to welcome Mrs Isabel Cottinelli-Telmo whose speech was extremely appreciated by the public in Palacio Fonseca.

The other speakers were:

- Mrs Simona Palacios et Mrs Laura Esteban, painting teacher and a well known painter herself, explained the history of the exhibition and mentioned how important this initiative was for people with autism;
- Mr. Verdugo, from the University of Salamanca spoke about "adulthood of the persons with autism". Mr. Verdugo emphasised the role of artistic activities.
- the University of Salamanca that allowed us to use the XVI century Fonseca Palacio as venue for the exhibition, also organised a press conference that had a large impact on the media.

Visitors admired the quality of the works and the amount of work artistic activities can mean for the artists. The innovative characteristic of the initiative and the large support received in all the countries which have hosted the exhibition was also mentioned.

It is possible to visit the exhibition on the website: <http://aut.tsai.es/museo>

For more information:

**ASOCIACION DE PADRES
DE PERSONAS CON
AUTISMO DE BURGOS**
C/ Valdenunez, 8
E - 09001 Burgos
Spain
Tel.: +34.47.46.12.43
Fax: +34.47.46.12.45

Membership to CERMI

On 15 October 1998, the General Assembly of disabled people representatives approved the membership as ordinary member of the Confederacion Autismo Espana and of Federacion Espanola de Asociaciones de Padres de Autistas/FESPAU in the Spanish Committee for Disabled Persons, CERMI. This is a step forward in the recognition of the specificity of Autism in all forums of disabled persons, at national or European level.

CERMI is the most important platform, officially representing the movement of disabled persons in Spain (about 2,5 million citizens).

CERMI is integrated to the main national organisations representing various groups of disabled persons: ASPACE (cerebral palsy), CNSE (deaf persons), COCEMFE (physical disability), FEAPS (mental disability), FIAPSAS (parents and friends of deaf persons), ONCE (blind persons), and Confederacion Autismo Espana and Federacion Espanola de Asociaciones de Autistas/FESPAU (persons with autism).

For more information:

Confederacion Autismo Espana
c. Guadiana 38
E-28224 Pozuelo de Alarcon
Tel.: +34 91 351 54 20
Fax: +34.91.637.77.62

NEWS FROM FRANCE

Creation of the association "Service-Familles"

An association understanding parents, their needs and their wishes related to the education of their child with autism: as any other child, his/her education is part of day to day life.

The aim of Service-Familles is not to propose techniques, but to develop a know-how through a continuous reflection on the behaviour of the person, on his/her needs and projects which will be elaborated in collaboration with the family.

After having contacted different associations (Autisme Loire - Autisme Forez), we stated that the main request of parents was to have somebody to care for their child between 16h/16h30 - 19h30 and on Wednesdays (when schools are closed).

Fathers and mothers are unanimous to report that when coming from school, specialised institute or any other kind of care, the child with autism takes up all their time to the detriment of the siblings and this can have bad consequences for the siblings and the parents. Parents are obliged to adapt their working hours to those of their children and this is not always well accepted by employers.

Furthermore, parents would like to have a social life, to visit friends, to receive them at home, to go to the movies, etc. When a need is met, other needs can emerge in the future. During our meetings with presidents of associations and with parents, the need for the creation of an association able to provide parents with persons able to take care of children with autism and to give support to parents emerged.

Another point was also raised: the reticence of parents to leave their child to a person they do not know and who may have no knowledge on autism.

As parents and professionals, we are involved in a relation of partnership with families to ensure them a continuous support.

Staff training is also very important. They have to receive clear information

and examples. They must be able to discover that they are no magic formulas but just individuals and unceasingly new situations.

Our aim will be to understand and adapt ourselves to the needs of parents. We take the opportunity of this relationship to show our respect to the person with autism. Last but not the least, our action will create new jobs.

Several partners are interested to join the association and are willing to contribute financially: CAF (Family Insurance) will help to finance a CLSH (leisure centre without accommodation) that will accommodate children with autism on Wednesdays and during school holidays in the best environment possible.

The association Service Familles will respond to the needs of the parents and of the associations.

For more information:

Service-Familles
1, rue des Mutilés du Travail
F- 42000 Saint-Etienne
France

Global Week on Autism

In Alsace

Traditionally, the first week of December marked the commemoration of the European Week on Autism. During the foundation of the World Autism Organisation on 21 November 1998 in Luxembourg, it was decided to create the Global Week on Autism. Autisme Alsace took this opportunity to launch its website and its electronic mail: a new way to facilitate exchanges with other associations from France and abroad. This is in addition of the bulletin of the association "Grain de Sel". The association can also be reached by phone.

Internet :
www.chez.com/autismealsace
E-mail :
autismealsace@chez.com

Furthermore, Autisme Alsace translated into French the guide written by Marc Segar - a young man with Asperger syndrome from UK - for other persons with Asperger syndrome (with no

learning disabilities). This guide is sold by the association. Theo Peeters, European expert on autism wrote the foreword. Sale profits will be go to people with autism of Alsace. During the Global Week on Autism, Autisme Alsace offered this guide to various persons with Asperger syndrome (about 10) in Alsace. The number of persons with autism in Alsace is about one thousand but there is no specific class for them nor centre of diagnostic.

For more information:

Autisme Alsace
4, Place de Geispolsheim
F-67230 Benfeld
Tel.: + 33 3 88 74 38 30
(Tuesday afternoon)

Internet:
www.chez.com/autismealsace

In Auvergne

The association ASF (Association de soutien et de financement pour les causes de l'enfance) and its president, Michel Dray, handed out, on Tuesday 8 December 1998, within the institution Sainte-Marie in Riom, a cheque of 40.000 FRF to the association Autisme Auvergne, also represented by its president Michel Baron. This cheque will enable Autisme Auvergne to purchase three or four tandem bikes that volunteers will use with the children "on the way of learning how to be free". After lots of efforts and patience, parents and educators came to very encouraging results with children, some are now attending regular schools. The primary school "la classe du soleil" welcomes this year two children with autism in l'école Sacré-Coeur in Riom, five children are now attending secondary school in a college in Sainte-Marie and three are on their way to start primary school.

For more information:

Autisme Auvergne
4, avenue Bergougnan
F-63400 Chamalières
France

NEWS FROM BELGIUM

VVA is re-organising

Since its origin the VVA wanted to be a parent association: working with parents, working for parents. As a consequence only parents of persons with autism can be members of the CA, the council of administration.

The VVA grew slowly but steadily: from less than 100 members in 1984 to more than 1.000 members in 1998. The range of activities did also expand. In 1982 autism was mentioned for the first time on television. In 1983 local contact groups were established. In 1984 the VVA started with its own magazine. From 1983 on conferences were organised on an annual basis.

Since there were no adequate services for people with autism in Belgium, the VVA tried to set up its own services. In 1985 the VVA started the first home training service focused on autism. These activities expanded from 400 sessions in 1984 to more than 2.500 sessions in 1997. The number of staff members increased from 1 in 1984 to more than 10 in 1997. The impact on the VVA became important. Not only because the gap between the subventions on one hand and the real expenditures on the other hand increased dramatically, but also because the effort of the CA of the VVA to (try to) manage this fast growing service took more and more time.

Another service was established to provide training and support of parents. In 1986 the VVA complied with regulations concerning social-cultural formation. The same history started again. As the service grew, the efforts by the VVA expanded as well.

The VVA was working very hard at many fronts. It were very tough times for the members of staff as well as for the CA. The VVA reached a point where the following difficult choice had to be made: do we want a further growth of our organisation? If yes, it was obvious the organisation ought to be enforced by professionals since parents-volunteers of the CA were no longer able to manage this rapidly evolving organisation. After long discussions the VVA decided in 1992 to run the organisation on a professional basis. This resulted in fundraising, media campaigns and further expansion of the existing services.

As a result the growth of the VVA accelerated. The number of staff members increased to 20, the budget to about 750.000 ECU of which about fifty percent covered by subventions.

The VVA needed again a period of reflection:

- what are we doing?
- are we doing the right things?
- are we doing it the proper way?

After a long period of meditation the VVA decided to go back to its roots: to be a parent organisation, to work with parents for parents.

Following considerations played a role in this decision.

- As stipulated in its statutes the VVA intends to be a parent organisation working for the interest of all people with autism. The management of the operational services took too much time and effort. As a consequence there was no time left to act as a parent organisation.
- Since different activities were organised by the same organisation a lot of confusion, ambiguities and misunderstandings arose. Not only within the organisation itself but also outside the organisation: towards its own members, subsidising authorities, and professional organisations.
- The VVA did not comply with the definition of a "real parent association".
- The CA of the VVA only including parent-volunteers, was no longer able to manage the organisation.

As a consequence of this decision the existing organisation has been split up in five different organisations. Each one has its own legal structure. As far as services are concerned, the re-organisation tries to comply with the different political structures and administrations of which they depend for subventions and other legal regulations.

The VVA wants to be a parent association

- lobbying
- awareness of parents, their setting, the "public opinion", the politicians
- partnership
- fundraising since the VVA doesn't get any subventions at all.

Only parents are members of the VVA-CA. Since the VVA is no longer involved or responsible for any operational services, it can act as a real, independent "consumer" (pressure) group.

The TBA, Thuisbegeleidings Dienst Autisme, organises the home-training sessions.

Subventions represent the major part of its budget. This service has to comply with all regulations imposed by the subsidising authorities. Parents as well as professionals can be member of the CA. The TBA is the one and only organisation responsible towards the subsidising authority as well as towards the politicians.

The VDA, Vlaamse Dienst Autisme, organises the "social-cultural" events including the edition of a magazine and other publications, training of parents, support towards services, running a documentation centre, organising conferences, ...

The same remarks of the TBA apply.

Autonom is responsible for all volunteers. Again the same remarks apply.

The DeBrug/VVA organises training of adults with autism. Again the same remarks apply.

New addresses and numbers

Central E-mail address:
autisme@xs4all.be

Internet-site
<http://www.autisme-vl.be>

Central fax-number
09/218.83.83

Telephone numbers
VVA 078/152.252
VDA 09/238.18.18
TBA 09/228.18.33
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Autonom 09/218.83.82

NEWS FROM ITALY

CTR PICCOLI i MILANO "Another point of view"

Report on the work undertaken in the field of the first social inter-subjective relations following the psycho-educational approach of the CTR PICCOLI - Territorial re-educational centre for children - via Vallarsa, 79 - Milan (Italy)

First of all, I will outline the process of diagnosis and evaluation used in our centre, because the foundation of our work is laid from the first contact with the family and the child.

The parents' experience

The evaluation begins with a meeting with the parents in the presence of the child. Our team is composed of three persons: the psychologist leads the talk, a therapist and an educator observe the interaction between parents/child and child/environment.

During this meeting we try to make the parents pinpoint the main problem at that moment. Then the parents and the team observe through a black mirror a free playing session, directed by the therapist.

During the meeting and the observation we determine the basis of the work that will be done later: the parents are invited to express their comments on the interaction of the child with the therapist. We ask them if the child's behaviour with a stranger corresponds with his regular behaviour, if they know ways to facilitate the interaction with their child, how he acts in their presence, in the presence of strangers, etc. These indications are sometimes used in real life situations in order to understand the special characteristics of this child. We have been able to verify the truth of Schopler's statement that the parents are the best experts on their children. The following step is the PEP test (psycho-educational profile test). The PEP permits to evaluate the competencies and the capacities of the child in given situations. We also ask the parents to describe the competencies of their child at home, so we can verify if s/he is behaving in the same way or not.

This stage allows us to understand how the child reacts to an adult asking him precise questions, what the parents think about their children's capacities, and how the parents agree on this matter. Sometimes we use the Leiter scale to evaluate the IQ or other development tests or functioning tests.

Role of the professionals

All these meetings give us all kinds of information, but they also allow us to have an idea of the viewpoint of the parents, of the image they have of their child, of their relationship with the child, and of the mechanisms they use to solve their problems.

After the tests (that take about 4 hours) a brief report is given to the parents and a new appointment is made for a next meeting without the child, at which we explain what we have deduced from the tests. It is very important that team and parents reach a very good common level of understanding of the child's problems.

We encourage the parents to formulate their wishes and we try to take these into account as much as possible in the intervention programme that we develop. This intervention programme is a collective work that has to agree to the needs of the parents. When the parents do not only share the work, but also understand its meaning, our treatment is situated in the intersubjectivity field. We think this is very important; just consider the work of Dawson, Newson, Stern, and the TEACHH programme. Our experience with the children has confirmed this conviction. The parents have told us about their incapability to communicate, to exchange messages with their children either by signs, by voice, by glances, or by a smile; and about the grief resulting from it, followed by giving up active involvement with the children.

We know that the development of communication starts naturally from the first weeks of life in the relationship with the mother. A child with autism encounters difficulties to establish durable interpersonal relations and so has little chance to understand intuitively the messages and information of

the outside world, due to his disability. Parents have the gift to teach their children everything in a natural way almost without being conscious of it. When raising a child with autism, this becomes extremely difficult and frustrating. The inborn talents of the parents are not sufficient to make the child progress in the fields where there are impairments.

The objective of our intervention is to find ways of communication that both parents and child can understand and to teach them to the parents after experimenting with positive results with the child.

The intervention has to:

- Establish the basis of an interpersonal relation, with the goal of lasting interactions that have a meaning to the child and to the person in front of him
- Develop the attention capacities so that the child can reach more adapted behaviour: glances, gestures (ex.: pointing), postures, rhythms
- Consider the child as a source of action, of emotion, of information so that the child is seen as a subject and not as an object.

For an effective intervention it is essential that the adult in front of the child has a very good knowledge about the characteristics of autism and can:

- Stay attentively and patiently in front of the child to be able to receive and recognise the smallest means of communication and exchange, to develop these subsequently,
- Accept the child with his/her characteristics including the stereotypes and the echolalies,
- Look for signs of two-way communication and try to develop them,
- Patiently propose games of exchange, with the voice, with the body, with other objects, movements like mothers do with babies; adapt them to the typical problems of these children who have the need to predict situations; and repeat them several times in the same way,
- Introduce the necessary "variations on the theme", more and more complex and accentuated, on the right moment, always bearing in mind the child's difficulties to accept them and to make use of them.

It is recommended that this intervention take place in a calm environ-

ment, made ready in function of the impending needs. This allows the reproduction of play situations and exchanges that are simple, predictable and repeated, and at the same time flexible. For an effective intervention, the work being done has to be applied in other places and in other relationships. We know very well that children with autism have problems generalising what they have learned in one context to other situations.

So it is advisable, even obligatory, to get the co-operation of the parents from the first encounter on. We ask them to participate actively in the intervention with the young child in order to let him make progress, at first in the field of two-way communication, and later on, step by step, in other fields.

We listen and we observe the bond they have with their children, their attempts to be close to their children, successful or not, and we take these into account to launch a therapeutic project that can be shared.

We tell what we have done during the treatment, showing it directly or on video, and we explain our objectives. We ask them to introduce work moments at home with the child, geared towards the same objectives.

We decide together with them what will be the role and the work of both mother and father. For this work we propose a certain period taking into account the energy and the availability of the family. We help them to create adapted spaces in their home, to study their child's periods and rhythms, to construct proper ways of interaction with the child, so s/he can make progress in the fields of intersubjectivity and communication. We support them regularly and methodically to up-date the planned programme: meetings, watching video together, periods of working with the mother at the centre during which she can repeat the games she has seen the therapist do just a moment before. The presence of the psychologist or the therapist can give the mother the strength to continue the work at home despite her sense of frustration. This support is very important because it is very tiresome and repetitive physically and emotionally, and the results are slow and limited, but sure.

*Cesarina Xai
Enrico Micheli*

NEWS FROM TURKEY

Centre for Children with autism

We started to build this Centre on 27th of August 1998 and planned to achieve it by the end of 1999. It is located in Kadiko y, Istanbul and will provide care for nearly 200 autistic children. The total resource area covers about 2800 square meters. It is specially designed for the needs of autistic children. It will be the first centre of this type in Turkey, it will include swimming pools, libraries, conference rooms. We also are planning to settle the offices of our organisation in its premises.

The current situation of children with autism in Turkey is not very good like most of the countries in the world. They have to receive education together with other disabled children, and this causes problems for them and for their teachers. This is something which we are trying to change.

We are already supporting a school in Istanbul for nearly 30 autistic children. This number of students is very insufficient so the new Autistic Children Support Centre will give us hope and happiness for the future.

F. Bi e S zer

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BOOKS

European Code of Good Practice to prevent violence and abuse towards the persons with autism

published by Autism-Europe with the support of European Commission DAPHNE initiative

Concern about harm suffered by people with disabilities has increased in recent years. Lifestyle often creates particular vulnerabilities, and in some cases intellectual difficulties can make reporting and giving formal evidence problematic. Suffering is usually 'invisible' to the public, policy-makers and politicians.

It is to remedy this situation that Autism-Europe decided to undertake this study with the support of DAPHNE initiative.

This Code has been drafted by an international team of experts in the framework of the fundamental principles of the Charter for the rights of persons with autism. The aim of this Code is to set up the basis for a coordinated action aimed to prevent violence and abuse toward persons with autism. Chapter One outlines the problem in general terms. Subsequent chapters identify the specific risk factors in relation to autism, prevention measures and recommendations for good practice. Finally, the concluding chapter gives an overview of the areas in which a Europe-wide approach could add a new dimension. This Code sums up the measures to prevent violence aimed at some specific groups: persons with autism, parents and professionals, parent associations, institutions, decision-makers and European institutions.

Price per copy: 250 BEF + 100 BEF (postage) = 350 BEF
 For 10 copies and more, price per copy: 200 BEF + 50 BEF (postage) = 250 BEF

French version also available

To order:

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 Avenue Van Becelaere 26B,
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Autism-Europe draft description of autism

Working group:
Catherine Barthélémy (F), Joaquín Fuentes (E), Rutger Van der Gaag (NL), Paola Visconti (I), Paul Shattock (UK, co-ordinator)

This draft is for Autism-Europe members only and is issued for the purpose of critical review and response to the working group. Only after the final document has been accepted and approved by the Council, acting on behalf of the membership of Autism-Europe it may be cited officially or used in decision making processes. Available upon request at Autism-Europe secretariat

(English and French versions, available on paper only. Please send your fax number or postal address)

Report of the European Parliament

on the report of the Commission concerning the evaluation of the third European programme for disabled persons (Helios II) 1993-1996 (COM (98) 0015-C4-0152/98). Available at Autism-Europe

Publications of European Disability Forum (EDF)

Guide on Amsterdam Treaty
 (about 60 pages, available in English, French, German, Spanish)

This guide gives a good overview of the treaty. It provides information on the opportunities and limits of the treaty for disabled persons.

Summary of the Guide on Amsterdam Treaty
 (8 pages, available in Danish, Dutch, Finnish, Greek, Italian, Portuguese, Swedish) Summary of the above-mentioned guide.

Manifesto for disabled women in Europe

(28 pages, available in the 11 languages of the European Union)
 This manifesto presents recommendations to improve the life of disabled women, gives references related to the promotion of equal opportunities for disabled women.

Recruitment Guide promoting the principle of equal opportunities

(140 pages, available in English, French, German, Spanish)
 This guide presents in brief some theoretical and practical aspects of the European recruitment procedure based on the principle of equal opportunities.

Leaflet on persons with complex dependency needs

(8 pages including a poster on the back, available in all E.U. official languages)
 This leaflet has been elaborated by the working group on persons with complex dependency needs chaired by the president of Autism-Europe. The aim of this leaflet is to raise awareness on the problems faced by persons with complex dependency needs or unable to represent themselves.

EDF presentation leaflet

(available in all 11 E.U. official languages)

These publications can be ordered at Autism-Europe. (Quantities are limited)

"Make it simple"

European Easy-to-Read Guidelines ILSMH European Association

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(available in English and French)
 The aim of these guidelines is to call on governments and organisations to make all public information services and documentation accessible for all groups of persons. The text must be easy to read and understand. This guide is a very efficient tool and should encourage people who are writing texts and providing information to produce texts easy to read.

The world disability report 99

The International Disability Foundation

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This report emphasises a simple truth that all human beings are born free and equal in dignity and rights. The report is intended to give the Disability Movement a stronger voice globally. (Article on Autism-Europe)

"Through the Eyes of Aliens"

**A book about autistic people
Jasmine Lee O'Neill
ISBN 1 - 85302 - 710 - 3
Jessica Kingsley Publishers**

Tel.: + 44 171 833 2307
Fax: + 44 171 8337 2917

This is a rich and positive description of how it feels to be autistic and how friends, family and the professionals that work with autistic people can be more sensitive to their needs. Jasmine Lee O'Neil, autistic herself, perceives the creativity, imagination and keenly-felt sensory world to the autistic person as gifts. She argues that "normalizing" autistic people - pushing them into behaving in a way that is alien to their true natures - is not just ineffective but wrong. In this vivid and enjoyable book, she challenges the reader to accept their difference and to celebrate their uniqueness.

Autism-Europe's view: An open door on the autistic world. Should be read not only by autistic people but also by all non autistic people involved in the care of autistic people.

"Attention Deficit/Hyperactivity Disorder"

**A multidisciplinary approach
Henryk Holowenko
ISBN 1 - 85302 - 741 - 3
Jessica Kingsley Publishers**

Tel.: + 44 171 833 2307
Fax: + 44 171 8337 2917

Attention Deficit/Hyperactivity Disorder (AD/HD) is a medical diagnostic label for a mixed group of disruptive behaviours in children, which influences their development, family relationship and social interaction. AD/HD is part of a child's make-up: it is not a disease, but a pattern of problem behaviour, much of which is largely outside the sufferer's control. This book provides clear guidelines on good practice in assessment, diagnosis and management of, and provision for, children with AD/HD.

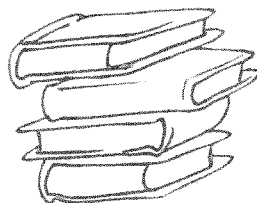
"Life behind glass"

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For Wendy Lawson, the world is indeed a strange place. It is noisy, confusing and full of contradictions. The people in it are distant and make no sense: why do they laugh and cry? why don't they say what they mean? Wendy lived with feelings of disconnection, anxiety and confusion for over 40 years before being correctly diagnosed with autism, or more specifically, Asperger's Syndrome. Wendy describes living her life as if "behind glass", watching the happenings around her, but unable to touch them. As a result, she has often been treated as if she is either deaf or stupid, when in fact she is neither. This book is about her determination to come to terms with the constraints of her condition.

Autism-Europe's view: Wendy's description of her experience will sound very familiar to many persons with Asperger's Syndrome. It demonstrates the importance of early diagnosis and adequate individualised support.



AVAILABLE IN FRENCH:

"Faire Face" Guide de survie à l'intention des personnes autistes

**Marc Segar
Préface de Théo Peeters**

Cet ouvrage traduit par Michèle Larchez, Docteur ès Sciences de l'information et de la Communication - DEA d'anglais (Sorbonne) - par ailleurs Présidente d'Autisme Alsace, a été rédigé par Marc Segar, jeune autiste britannique atteint du syndrome d'Asperger. Marc est décédé en décembre 1997 d'un accident de voiture à l'âge de 24 ans. Diplômé en biochimie, l'auteur a choisi de travailler en tant qu'animateur pour enfants et de donner des conférences sur l'autisme. Unique en son genre, cet ouvrage écrit par un autiste s'adresse d'abord aux autistes, et vise à leur donner accès aux règles "non écrites" qui régissent notre société. Très utile aux professionnels, aux familles et amis autistes, il leur permet de se glisser dans la peau d'un autiste et de mieux percevoir les contraintes et les frustrations liées à la façon dont les "non autistes" que nous sommes, conçoivent le monde. Le bénéfice de la vente de ce livre est dédié aux autistes d'Alsace. La traduction, la saisie et la mise en page de l'ouvrage ont été effectuées à titre bénévole.

Point de vue d'Autisme-Europe: ce livre s'adresse avec respect, tendresse et humour aux personnes autistes et leur donne une foule de conseils très utiles pour leur vie quotidienne. Toute personne intéressée par l'autisme y trouvera également une mine d'informations qui lui permettront de mieux comprendre le mode de fonctionnement des personnes autistes.

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99 FF par exemplaire + frais de port

Notice: this guide is also available in English (see LINK 22). Please contact Autism-Europe secretariat

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REPLY COUPON

6TH CONGRESS AUTISM-EUROPE MAKING OUR DREAM REALITY

GLASGOW 19 - 21 MAY 2000

REMINDER AND SECOND CALL FOR PAPER

Link is published by **AUTISM-EUROPE** with the support of the European Community - Actions in favour of the Equalisation of Opportunities for Disabled People

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Articles and information for next issues of Link are welcome. They should be sent to the address hereabove.

Link est aussi publié en français.
Si vous souhaitez recevoir notre revue en français, veuillez en avvertir notre secrétariat à l'adresse ci-dessus.

The first deadline for the receipt of proposals was 28th February 1999 and a large and impressive range has already been received and will be considered by the Programme Committee.

The Committee is aware that the relevant information did not reach all quarters until recently and in order to allow a full participation and to encourage the presentation of very new material, we are issuing a second (and final) call for papers. The final deadline is 31st May 1999. The Committee will meet soon after the date to prepare the programme.

The 6th Autism-Europe International Congress will be held in Glasgow, Scotland in May 2000. It is jointly organised by Autism-Europe and the Scottish Society for Autistic Children. 2000 delegates are expected to attend.

Aims and theme

The purpose of the Congress is to provide a platform for sharing the best research and latest knowledge in autism amongst parents, professionals and policy makers. The theme : Making our Dream Reality, has been chosen to encourage an emphasis from contributors on the practical applications of research and on experience, in addition to pure research.

Congress Format

The Congress will consist of an integrated series of plenary sessions by internationally recognised speakers, smaller specialised presentations and poster presentations from a range of people involved in autism at all levels, and exhibitions. The newly built conference centre has the latest technical equipment allowing for presentations to be made using the most up-to-date video and computer compatible technology whilst also catering for more informal presentations in smaller spaces.

Call for Papers

The Scientific Committee wishes to produce a balanced range of presentations and is calling for proposals covering all areas relevant to autism including biological, psychological, medical, service provision, legal aspects, political issues.

Who is invited to submit ?

The Committee wishes to encourage contributions from a wide-cross section of those involved in autism and would particularly welcome proposals from people with autism or Asperger syndrome, parents, and voluntary groups, as well as from professionals including researchers, clinicians, psychologists, educationalists, practitioners at all levels, policy makers, students, etc.

Languages

Proposals should be submitted in English or French. At a later date, dependent upon response, interpretation facilities may be available from other languages.

Proposals should include:

Presenter: Name, full postal address, telephone, fax, e-mail address
Title of Proposal
Brief abstract (200-300 words)
Indication of whether proposals is for verbal, video or poster presentation

Deadline for Proposals:
31 May 1999

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