

Second Interim Report to the European Commission DG-SANCO for:

Grant Agreement No.:2005112 (790655) EAIS.

December 2007

In this report, Annex documents, which are available online, have not been printed as part of Hope Project's environmental protection policy. Internet links are provided.

Project Activities

Work Package Activities and results for the period and plans for the next period

Work Package 1: Coordination of the Project

The European Autism Information System project has achieved important advances over the past twelve months; the main partner of the project has arranged two coordination meetings; the first meeting in London on February 28, with participation mainly of the associated partners and the achieved objective of mutual agreement about the preparation of pilot studies protocols. The second meeting, "Second Panel of Experts on ASD" was held in Luxembourg, on September 24-25. The latter was financially supported by DG-SANCO with the participation of collaborating partners and Autism Speaks as an observer with the achieved objectives to obtain a better common understanding of proposed methodology for pilot studies, consensus of proposed tools and to agree a timeframe for implementation. The Hope Project was involved in organising all practical aspects of these international meetings as well as steering their content to be as productive and as appropriate to the needs of the project as possible. Also, two telephone conferences have been carried out to aid coordination between Work Package leaders on areas of work which overlap and can benefit from synergies in the preparation and implementation of their work.

The project leader has met with Collaborating Partners on several occasions in person, in connection with establishing suitable pilot areas for the EAIS project, including a Public Health Agency in Luxembourg, University College Dublin and Autism Europe in Brussels.

Day-to day communication with partners has been maintained by e-mail, post and telephone. This includes monitoring work package progress, organising meetings and maintaining contact with, and records of, over 40 Collaborating Partners and experts in the field of autism.

As a result of the participation of the main partner in the International Autism

Epidemiology Network meeting and the International Meeting for Autism Research, both held in Seattle, in May this year, important contacts were made with different organisations, including Autism Speaks, which has been identified as a potential co-financing partner. A proposal for augmentation funding, entitled 'European Autism Information Centres' was made to Autism Speaks in November 2006 but as yet there has been no definite response regarding funding.

The website www.eais.eu has been updated considerably over the past twelve months and now has 48 signed up members, who can access technical papers, questionnaires and other tools, minutes of EAIS meetings as well as news items and EAIS Newsletters and reports.

Plans for the final period in the Coordination work package are primarily connected with the search for further funding in order to carry out pilot studies as described later in this report, based on the validated protocol, which is an output of the EAIS project. An important strategic aspect in the development of an information system for autism is the creation of Autism Information Centres across Europe. These centres will be coordinated by local partners, following the harmonised protocols developed in this project.

Work Package 2: Dissemination of the Results

The main objective of WP2 is to disseminate information on the project "life" and outcomes, bearing in mind that dissemination activities are closely linked with outcomes of the other work packages.

To date, the following activities have been carried out:

1. Ulss20 Verona has contributed to the updating of the EAIS website with relevant information and outputs of the project activities, uploading the list of collaborating partners on the EAIS website and ensuring that a brief description of all the project partners has been uploaded on the web site. Furthermore, Ulss20 Verona has proposed some changes to the structure of the website to ensure that it is user-friendly for persons with disabilities. Finally, Ulss20 Verona has translated the contents of the website into Italian in line with the initiative of the project leader to create a multi-language version of the web site.
2. The first edition of the bi-annual newsletter was prepared by University College Cork, edited by Hope Project and sent via email by Ulss20 Verona to the EAIS mailing list in June. Hard copies of the newsletter were also sent to the Associated Partners and key stakeholders connected with the project both in the European Parliament and in the European Commission.
3. In line with the objectives of WP2, Ulss20 Verona have designed a brochure containing all the information relevant to the project. One thousand copies of the brochures have been printed. Two hundred copies were distributed at the official launch of the EAA (European Autism Alliance) held in Brussels on 17th October 2007 in the European Parliament. The remaining copies have been distributed amongst the partners (See Annex 1)

4. Ulss20 Verona have designed a project logo in order to create an identity for the project. In consultation with the project leader, a colored cube, which recalls the Rubik cube, was selected as representative of the complexity of autism. The dot on the “i” of EAIS is the EU flag, ensuring that the European nature of the project is also represented. (Please see brochure)
5. Ulss20 Verona have coordinated the publication of an article in the Italian edition of *Vanity Fair* to raise public awareness on the condition of autism. *Vanity Fair* is a widely-read magazine that has different editions in different countries and deals with a range of topical issues. Both Dr. Maurizio Brighenti and the head of a local parents association were interviewed in the article. (See Annex 2).
6. On the occasion of the EAA launch, Ulss20 Verona coordinated the presentation a slide-show with photos of children with autism taken in the Autism Centre of Verona under the co-ordination of Dr. Maurizio Brighenti, Director of the Centre. The Hope Project engaged the photographer Lidia Costantini to produce the photos. The slide show consisted of a series of black and white portraits (83 in total) of 6 children between the ages of 5 and 18. The photographs were taken during the therapy sessions of the children as well as during their playtime. The slideshow was accompanied by background music “Enjoy the Silence” by Depeche Mode. Discussions are ongoing with the project leader concerning the organisation of a touring photo exhibition with a selection of the best photos.

Plans for final period

- Update website
- Research of Media and Broadcasting events (e.g. magazine, newspaper, TV shows, ...) related to autism
- Organisation of a touring photo exhibition, possibly at national and European level (e.g. European Parliament)
- Research of relevant events for disseminating the project information
- Dissemination of the brochure during meetings or conferences
- Research of other funding opportunities

Work Package 3: Evaluation of the Project

Evaluation of the project has so far been carried out through coordination meetings and communication with the partners. After submitting this Interim Report, an evaluation report will be written in January, to assess the level of achievement of the project and its components in terms of deliverables and outcomes. In terms of achieved deliverables according to the project proposal, the following deliverables have now been completed:

- D1 List of European Institutions
- D2 EAA Statutes http://www.eais.eu/downloads/EAA_Vision_Document.pdf

Work Package 4: Development of a European Network

The development of a European Network for autism is a key component of this project. The name of the network is the European Autism Alliance (EAA) and plans for the EAA were researched and developed by the Hope Project in the early part of the project. The launch of the EAA took place in the European Parliament in October 2007, organised by the Hope Project and presented by Kathy Sinnott ID, Maria Carishamre ALDE and Den Dover EPP all members of the European Parliament. Eminent speakers from Europe and the United States of America took part in the event, see website www.eais.eu which was attended by stakeholders in the issues of autism: patient and family support groups, health professionals, public servants and politicians. The EAA Vision Document, which was presented at the launch, can be viewed in Annex 4 of this report.

Part of the strategy to achieve sustainability of the EAA after the current project ends, is the formation of a lobbying group of MEPs with a special interest in autism, to promote political support for the EAA and to encourage member states to enrol government bodies in the Alliance. We have also, with the support of Autistik, one of the Associated Partners of the project, continued to actively campaign for the adoption of autism as a health priority for the Czech Republic Presidency in 2009.

Work Package 5: Improvement of Personnel Expertise

For this work package, University College Cork is forming a distance-learning platform. The distance learning platform was set up on blackboard through UCC. However it was thought that it would be easier for the platform to be set up on the project website (www.eais.eu). Over the past year, research has been carried out on how the distance learning platform should look and how the information from other partners is going to be presented. There is a large amount of work that has been developed by the project (for example, questionnaire tools, protocols for prevalence estimates and financial burden estimates, functional guidelines and the EAA concept) and we are in the process of finalising these outputs in preparation for presenting these new resources in a medium that can be used for the improvement of personnel expertise to the benefit of interested stakeholders.

The creation and completion of two newsletters that were then distributed by ULSS 20 Verona will also contribute to furtherance of knowledge in the area of ASD information. These newsletters were prepared by University College Cork with contributions from the other Associated Partners and Collaborating Partners and editing by the main partner.

Work Package 6: European Population Based Surveillance System for ASD

During this period, Aarhus University has worked on refinements of the software-program proposed to work as basis for pilot studies for the European Autism Information System. Steps 1 & 2 have been carried out, and Step 3 initiated (see below).

Step 1: Collect information from participating countries/centres on existing infrastructure for autism spectrum disorders (ASD) surveillance from meetings, interviews/questionnaires, and also by exchange of available data on existing registries/systems.

Step 2:

- Through international meeting and work groups, identify gaps in existing ASD surveillance infrastructure and develop approaches to address gaps.
- Issues to address:
 - Criteria for common ASD case definition.
 - Common data elements for ASD information system and data collection protocol.
 - Quality assurance measures for ASD information system.

Step 3:

- Conduct pilot studies at select sites to evaluate feasibility of recommended data collection
- Protocol and validate data, especially ASD case definition.

The *Fundación para la Salud y Cooperación Internacional Carlos III* have tested the ASD registry software built by Aarhus University and has provided a first report with one of the first versions sent to us in Microsoft Access format. After discussions held in the ASD experts' meeting in Luxembourg in September, hosted by DG-SANCO, we again tested a new version of the software in Microsoft Access. This last version is accessible through a particular username and password for each participant partner. The procedure of testing has consisted on entering some input data of Spanish ASD cases from different regions (Madrid and Salamanca – For this purposes, it was necessary to spent some funds to travel to Salamanca). In summary, two reports have been written by *Fundación para la Salud y Cooperación Internacional Carlos III*, with several suggestions for improvement and adaptation to this registry application. An other pilot area who has been testing the database is Grenoble in France who already presented a first report of the results of the database testing. These reports also include some errors detected and general comments on the different screens, variables included as well as absent variables that are important for their work in Spain.

Fundación para la Salud y Cooperación Internacional Carlos III have also coordinated activities with the leader of this work package to participate in the workshop held in May in Seattle with regard to ASD registries. This workshop was organized by CDC and Autism Speaks and they have funded the creation of a working group for this topic at a global level, in which both Denmark and Spain partners are active members.

Work Package 7: Characteristics of ASD in Europe

This work package is jointly led by *Fundación para la Salud y Cooperación Internacional Carlos III*, focusing on the prevalence aspect of ASD in Europe, and King's College London, focusing on the financial burden of ASD in Europe.

The partner *Fundación para la Salud y Cooperación Internacional Carlos III* has been developing a study design for ASD prevalence, and defining an strategy to implement a pilot study for estimated prevalence, at European level. During this period, a document entitled "*Strategy for the Development of an ASD Prevalence Estimate within the framework of the EAIS project*" has been defined and completed. In this document a framework of necessary activities to conduct a prevalence study have been both defined and designed.

This document (see Annex 5 of this report) includes a general scheme of the procedure and descriptions and annexes for each part of the procedure and is available to download from the EAIS website. Annex-1 of the document is the *EAIS Questionnaire* developed during 2006 that explores the situation of the several services such as health, educational, social and parents' organizations in the participant country/region. Annex-2 is the *Report on Q-EAIS results* that was presented and distributed at the meeting held in Luxembourg in September 2007; this is the first descriptive and comprehensive report of the Q-EAIS results and includes an analysis of 11 questionnaires collected in the first phase of the project. Six of these responses come from collaborating partners and the other five from associated partners. It shows the differences existing on diagnosis and detection, health care system, educational and social facilities and patients' organizations for ASD in different countries where the European project is being carried out. Finally, this report has been sent to CDC experts attempting to get feedback.

Annex-3 of the document is the *First Draft Protocol Study Design* and also a comprehensive strategy to develop a prevalence study in some European countries. Justification, background, and all the issues important to considerate in ASD prevalence studies in Europe are gathered. Objectives, setting, population, sources of information, case ascertainment procedures by stages, data collection system, instrumentation and statistical analyses are the main chapters about among others in this specialized document. This document is the first step to design a harmonized European Protocol for Autism Prevalence (EPAP). This study will provide the strongest and most robust evidence available to determine the prevalence of ASD in the EU. We are currently waiting for the feedback of the Expert Panel. Professor Eric Fombonne is currently reviewing it and will send us his comments.

Furthermore we have developed a short checklist titled "*Checklist for selecting places of piloting and exploring difficulties for a prevalence study in Europe*" which represents Annex-4 of the document. This checklist has been sent to the partners willing to carry out a pilot prevalence study in the whole country or in one of its regions. At the moment we are waiting for the answers in order to define the list of partners definitively involved although we have already received five responses.

Regarding the feasibility study (for carrying out a pilot study) we have made the relevant contacts and we have started dealing with organization matters in order to be able to start as soon as possible. In fact, we are preparing to three of the Spanish regions to implement this pilot feasibility study.

Also along the process of developing the "*Report on Q-EAIS*" we have detected some questions now included in the Q-EAIS questionnaire that could be improved. That is why, a second draft version of the Q-EAIS (Q-EAIS Modified) has been built

in order to improve and facilitate an aggregated data analysis in the next future what will represent the annex 5 of the main document after making the accurate modifications to the original “Q-EAIS”.

Our tasks in this WP have also consisted on collaborating with Dr. Martin Knapp and his colleagues in developing how to get the appropriate information for conducting the financial burden of ASD at European level. Specifically, we have filled the “Financial burden pilot scoping exercise” sent to us by the responsible of this study.

All of the documents and annexes already mentioned are available to download from the EAIS website (<http://www.eais.eu/>)

In the meantime we have published the paper titled “Estimating the Burden of Disease for Autism Spectrum Disorders in Spain in 2003” in the Journal of Autism Developmental Disorders” (Sánchez-Valle E, Posada M et al. 2007. J Autism Dev Disord. 2, DOI 10.1007/s10803-007-0393-1). In this paper, a standardized method to estimate the burden of disease for ASD in Spain is presented

King’s College London, the other Work Package leader in WP8 has designed a scoping questionnaire, which was sent out to Associated and Collaborating Partners. This questionnaire was sent to get an idea of what data is available on where children with ASD live and the impacts on services and families in each of countries. There are three main sections covered in the questionnaire, these include: accommodation, service receipt and impact on families.

A summary of a draft analysis plan to estimate the financial burden of ASD at the European level is described below. However it is important to note that before this plan can be implemented all questionnaires need to be analysed to get a picture of what data exists across each of the sections.

Described at the last meeting in Luxembourg was a modular approach which covers five elements. This approach has been recently used to estimate the cost of autism in the UK (Knapp et al. 2007). The specifics of this approach will be ironed out when information is returned by the partners on what data are available and from whom.

Prevalence estimates

Estimates of prevalence in each of the pilot sites will be estimated from the epidemiological study.

Age Group

Given the heterogeneity of needs and circumstances – and hence probably also of costs – within the group of people with ASD, it would be useful to estimate prevalence by age related groups within the population.

We may therefore distinguish the following groups:

- Pre-school children (ages 0-3) by level of functioning or diagnostic categorisation
- Primary school children (ages 4-11) by level of functioning or diagnostic categorisation
- Secondary school children (ages 12-17) by level of functioning or diagnostic categorisation

- Adults (ages 18 and over) by level of functioning or diagnostic categorisation

Place of residence

For each subgroup defined by age (e.g. primary school children by level of functioning) we would want to look for estimates of the costs of support. Because those costs are driven by the accommodation setting within which an individual lives, we may first want to describe the distribution of people with ASD across different accommodation types.

Costs

Data obtained from the scoping questionnaire would be used to get an idea of the information sources from which accommodation, service use data and impacts on the family could be available.

Unit costs

UK specific unit costs could be attached to service use data for all countries. These costs will then be converted using an appropriate conversion method to Euros.

Aggregate costs

The final stage would be to pull these various data together – using prevalence rates applied to each country's population figures to calculate numbers of people with ASD in groups distinguished by age and level of functioning.

Reference

Knapp M, Romeo R, Beecham J (2007). The economic consequences of autism in the UK. Foundation for People with Learning Disabilities.

Work Package 8: Harmonised Early Detection Tool

The objective of this Work Package is to draw up guidelines for early diagnosis on the basis of a comprehensive analysis of existing tools and methodologies.

Note: to facilitate reading of this report, as the activities are sequential, reference has been made also to activities carried out in the first reporting period (from 01/01/2006 to 31/10/2006).

To date, the following activities have been carried out:

- Bibliographic research on the main tools needed for Early Detection;
- Analysis of the most significant indicators present in each tool for Early Detection;
- Comparison between these indicators and tools to identify the most complete in terms of response in identifying autism;

- Presentation of the WP8 activities at the panel of experts' meeting in Luxembourg (September 2006);
- Contact with Autism Speaks and CDC for drawing up the guide lines for early identification of Autism;
- Bibliographic research of literature on procedures used in Early Detection;
- Formulation of a model for the early identification of alarm signals which may point towards autism. Work presented at the Panel of experts' meeting in Luxembourg 2007.
- Collection of family videos for early identification of alarm signals in the first 3 years of life, in order to prepare a video tool.
- Utilization of CDC Atlanta protocol for the study of the child's behavior, in order to prepare/organize the mentioned video;
- Preparation of questionnaires, to evaluate the awareness on the autism topic, for pediatricians and NPI Services in selected areas.

Work Package 9: Increased Public Awareness

Work has been carried out by the lead partner in this work package in the following areas in the Czech Republic; The following report indicates work carried out in the Czech Republic with a view to expanding these activities. The Project Leader had intended visiting Autistik, the Work Package leader for WP9 during the year in order to further this process of expansion of the Public Awareness aspect of the project. However, this was not possible due to time constraints and is contemplated for the next period so that the experiences from the Czech Republic can be used in the Distance Learning Platform and other project outlets.

- Evaluation and distribution of the new book 'Think and Create' (new ideas for teaching children with autism), which is a handbook for teachers and parents
- Practical training for parents (summer school): 38 participants, 14 days. The programme consisted of a theoretical part, looking at basic information on the autistic triad, problems with the theory of mind, weak central coherence, executive functions, generalisation skills etc and a practical part of the course which involved individual assessment of each client with autism, practical training of how to care for and teach the child with autism – academic skills, self help skills, communication skills, social behaviour etc. The theoretical part was based on new scientific knowledge, in the practical sessions, modern approaches to children with autism were used and great attention was paid to parents' priorities and to siblings' programmes.
- **DVD information set (four pieces)**

1. Information about early diagnosis-distributed to specialists in medical science
2. Information about schools and educational approach-distributed to schools
3. Structured teaching with visual support- distributed to educational institutions
4. AUTISTIK-information about NGO. Focus on parents' role in the education of children with autism. Information about legislation issues etc.

In addition to these, other awareness-raising activities included radio programmes, and social events.

Lobbying activities continued, with letters and meetings to promote the adoption of autism as a health priority during the Czech Presidency of the EU in 2009.

Nov 06 - Oct 07	Main beneficiary	Associated beneficiary	Associated beneficiary	Associated beneficiary	Associated beneficiary	Associated beneficiary	Associated beneficiary	Associated beneficiary	TOTAL
	The Hope Project IE	AUTISTIK CZ	King's College London GB	Fundación Carlos III FCSAI-IIIER ES	Institute of Public Health NANEA DK	ULSS 20 Verona IT	University College Cork IE		
Expenditures									
<u>Direct eligible costs</u>									
E1. Staff	58,800	10,378	5,545	38,926	35,222	36,704	25,559	211,134	
a. Costs not pertaining to national officials	58,800	10,378	5,545	38,926	35,222	36,704	25,559	211,134	
b. Costs pertaining to national officials									
E2. Travel costs and subsistence allowances	5,695	2,405	168	1,332	1,026	1,411	1,770	13,807	
E3. Equipment	7,855	850	1,660			2,399		12,764	
E4. Consumables directly linked to the project	277					2,250		2,527	
E5. Subcontracting costs	6,452							6,452	
E6. Other costs	3,250	3,800				3,795		10,845	
Total direct eligible costs	82,329	17,433	7,373	40,258	36,248	46,559	27,329	257,529	
<u>Indirect eligible costs</u>									
E7. Overheads	5,763	1,220	516	2,138	2,537	3,259	1,913	17,347	
Total - Expenditure	88,092	18,653	7,889	42,396	38,785	49,818	29,242	274,876	



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Information for second Interim Report to the European Commission DG-SANCO

Annex 2





VANITY DENTRO IL GUSCIO

I BAMBINI NON CI GUARDANO

EDOARDO SOFFRE DI **AUTISMO** E VIVE ISOLATO IN UNA PRIGIONE TUTTA SUA. MENTRE PARTE DALL'EUROPARLAMENTO UN'INIZIATIVA PER RENDERE MENO MISTERIOSA QUESTA MALATTIA (PERCHÉ ENTRARE NELLA PRIGIONE DI EDOARDO, E APRIRNE LA PORTA, È POSSIBILE), SIAMO ANDATI A VERONA. E ABBIAMO VISTO IL POTERE DEL SORRISO

DI MARIANGELA MIANITI - FOTO LIDIA COSTANTINI

Edoardo, 7 anni, uno dei pazienti del Centro di cura dell'autismo di Verona.

250 VANITY FAIR 11.10.2007

Appena ho guardato queste foto, mi ha colpito lo sguardo perso di Edoardo, poi il sorriso di Martina che sbucca da un materasso su cui sta giocando. Edoardo e Martina hanno 7 e 8 anni e in comune una malattia, l'autismo. Quello sguardo e quel sorriso rappresentano i due confini di questo disturbo: la realtà e la possibilità. Le immagini sono state realizzate nel Centro di diagnosi, cura e ricerca sull'autismo di Verona, uno dei migliori in Europa. Ci sono voluti due mesi per scattare perché in questi spazi, dove lavorano 15 operatori specializzati, bisogna entrare in punta di piedi, osservare, capire, conquistare la fiducia e stabilire un contatto

«SONO BAMBINI NORMALI, FINO A UN CERTO PUNTO DELLO SVILUPPO. POI, D'IMPROVISO, SI ISOLANO, NON PARLANO, VENGONO SCAMBIATI PER SORDI»

epidemiche: un caso ogni 166 bambini. Ce ne sono di più perché si conoscono tutti i casi o perché i più piccoli si ammalano più facilmente in America? Finché in Europa non si arriverà a un sistema comune di monitoraggio, non lo sapremo. Di sicuro i casi stanno aumentando. Per questo il 17 ottobre si terrà al Parlamento Europeo il lancio ufficiale dell'Eas (European Autism Alliance), che vuole creare una rete per unire tutte le associazioni che si occupano di autismo. Perché di questa malattia si sa poco, anche tra molti pedi-

no messo a punto una cura che si concentra sul comportamento. Alcuni cambiamenti nel modo di fare parlare e reagire del bambino sono le prime spie. I segnali di allarme sono precisi ma difficili da cogliere e compaiono nella prima infanzia, fra i 6 e i 24 mesi. Ci sono diagnosi però che vengono ancora fatte fra i 4 e i 6 anni. «È una perdita di tempo enorme», dice Briglienti. Le prime ad accorgersi che qualcosa non va, racconta, sono le madri: «Nella maggior parte dei casi questi bambini sono normali fino a un certo punto del loro sviluppo. Poi, all'im-

vai il centro di Verona. Abitavo a Firenze, avevo un lavoro e una casa appena acquistata. Per poter curare mio figlio ho lasciato tutto quello che avevo, mi sono trasferita qui e ho ricominciato da capo».

«QUANDO MATTEO MI HA FATTO CIAO»

Breakdown, «crollo», «spina staccata», «fine delle trasmissioni»: questo succede a un autistico. Continua a sentire, ma non comunica più. «L'incapacità di parlare e di interagire», spiega il dottor Briglienti. «provoca frustrazione in questi bambini, che capiscono e provano emozioni, ma non sanno come manifestarle. Succede allora che a momenti di totale assenza si alternino

segnare loro a vestirsi, a rispondere. Ogni settimana arrivano 53 bambini nel nostro centro e incontrano logopedisti, lavorano sulla psicomotricità, seguono trattamenti medici, imparano a comunicare anche con il computer». E i risultati si vedono: «L'altro giorno ho incontrato un piccolo paziente in corridoio e la madre gli ha detto: "Matteo, saluta il dottore". Lui non mi ha guardato, però ha detto grazie e ha fatto ciao con la mano. Questo significa che ha imparato a reagire, a salutare col gesto, ma non lo sa coordinare con la parola. In quel contesto era sbagliato dire "grazie": vuol dire che dobbiamo lavorare ancora sul linguaggio». Per capire quali progressi i bambini stanno facendo, e per aggiornare la te-

crisi, bisogna cercare di capire prima di tutto che cosa l'ha provocata». Con la terapia molti migliorano, e per le famiglie significa riuscire a fare una vita più normale. L'autismo infatti non gravola solo sul bambino, ma colpisce anche loro. «I nostri figli hanno bisogno di avere sempre accanto qualcuno che sappia come trattarli», dice Marzia. «Ci sono genitori che hanno smesso di lavorare, o cambiato lavoro per fare dei turni, o scelto il part-time. In molti casi le coppie si separano, con il risultato che sul genitore a cui è affidato il bambino cade la fatica più grossa. I bambini autistici hanno un'energia inesauribile, molti dormono poco e si svegliano alle due o alle tre del mattino, allora bisogna essere pronti e stare con lo-



Marco, 6 anni, la scrittura di Lorenzo, 7, e un terapeuta che tenta un contatto visivo con Mirco, 17.



La rabbia di Salvatore, 13 anni; i giochi di Edoardo, 7, e Martina, 8.

to con i bambini che seguono i corsi di psicomotricità, logopedia, gioco, educazione. Nato dieci anni fa anche per le richieste di molti genitori che cercavano risposte su questa malattia, il centro, che fa capo all'Usl 20 di Verona, è diretto dal professor Maurizio Briglienti e inserito nel progetto Eais (European Autism Information System), cofinanziato dall'Unione europea. L'obiettivo qui è anche quello di cercare una strada comune nella terapia e nella diagnosi, perché in Europa per ora ci sono diversi metodi, e spesso non coincidono. Così, non essendo monitorati con un unico criterio, non si sa nemmeno quanti sono i casi di bambini autistici nel nostro continente. Si fanno studi in Italia si parla di uno ogni mille e si sa che il rapporto maschi-femmine è di 4 a 1. Negli Stati Uniti, dove l'autismo è trattato in modo omogeneo, si è arrivati a cifre

tri, con il risultato che si arriva tardi a una diagnosi. «CITTÀ, LAVORO, CASA: PER LUI HO MOLLATO TUTTO». Ritardare le cure può fare una differenza enorme, perché l'autismo, se diagnosticato e curato presto, può attenuarsi o addirittura svanire. «Nell'ultimo anno abbiamo tolto le diagnosi di autismo a 4 bambini fra gli 8 e i 12 anni che sono stati in cura da noi», dice il professor Briglienti. Anche questo spiega perché in questo centro, dove sono stati visitati mille bambini in 10 anni, ci sono liste di attesa di due mesi da tutta Italia per iniziare la terapia. La malattia è di tipo strano, perché inafferrabile, sfuggente, tant'è che anche la stessa sigla che la identifica, Asd (Autism Spectrum Disorders) definisce i sintomi come «disordini». Le cause potrebbero essere anche genetiche. In attesa di risposte precise, a Verona han-

provviso, accade un **breakdown** evidente, un "crollo". Perdono il sorriso o sono poco partecipi, tendono a non rispondere, spesso sono scambiati per sordi. Riducono il gioco e iniziano a fare gesti e attività monotone, ripetitive, non cercano più gli altri, si isolano. Allora **la madre corre dal pediatra, ma spesso si sente rispondere: «È normale, signora. Non si preoccupi, è un maschio e i maschi si sa che parlano un po' dopo».** È successo così anche a Marzia Legnami, mamma di un bambino autistico di 9 anni. «Mio figlio aveva 18 mesi quando mi accorsi che qualcosa non andava. Fino ad allora era stato allegro, vivace, socievole, curioso, riconosceva già tutte le lettere dell'alfabeto. Poi comincio a chiudersi, aveva sempre quello sguardo vuoto, dove lo mettevi stava, senza reagire: sembrava un peluche. Il mio pediatra non si allarmò, ma mi preoccupai e cercai finché tro-

«MIO FIGLIO, SEPPUR SENZA GUARDARMI, MI HA SORRISO DAL MOMENTO CHE L'HO PRESO A SCUOLA. QUEL SORRISO, PER ME, È IL SOLE»

crisi di rabbia, autolesionismo, violenza improvvisa e apparentemente immotivata. «A volte», dice Marzia, «basta cambiare posto a un oggetto per scatenare una crisi. A volte può essere anche un colore a irritarli. Mio figlio, per esempio, appena vede il verde degli spinaci, anche da lontano, prova nausea e si agita». Molti non guardano mai in modo diretto. Altri ancora fanno gesti ossessivi e ripetitivi con le dita e con i polsi, oppure continuano a battere il palmo sulla bocca aperta. L'obiettivo del progetto Eais (*European Autism Information System*) è toglierli da questa apatia. Come? «Bisogna lavorare sul comportamento», insiste Briglienti, «coinvolgerli, farli giocare, spingerli a reagire, in-

rapia, è necessario insegnare alle famiglie e agli insegnanti che cosa osservare e come reagire, come continuare la terapia a scuola e a casa, come comportarsi quando arrivano le crisi, come interpretare le reazioni dei bambini. «SVEGLIA ALLE DUE DI NOTTE PER STARE CON LORO». «Abbiamo imparato a fare continuamente domande ai nostri figli», dice Marzia, «a parlare loro di continuo, a prepararli momento per momento a quello che si farà insieme, perché sono abitudinari e possono reagire malissimo a un cambiamento. Vanno accompagnati con dolcezza, dicendo loro: "Adesso mangiamo, poi andiamo a giocare e dopo facciamo il bagno". Se hanno una

ro. Nei casi peggiori i genitori separati litigano sulle terapie da seguire anche a suon di carte bollate, ma, poiché non ci sono cure ufficialmente riconosciute, i giudici non possono prendere nessuna decisione. Anche per questo è importante che in Europa si arrivi a un protocollo comune sulla diagnosi e le terapie. Se penso a tutti quelli che potrebbero essere curati meglio... È sera, sono a casa, accendo il computer e vedo un'email di Marzia. Scrive: «Ci tenevo a dire un'ultima cosa. Questi ragazzi sono in grado di insegnarci molto e darci molto. La pazienza che noi troviamo ci viene dalla forza che ci trasmettono vedendo come combattono tutti i giorni. Oggi è stata una bella giornata. Mio figlio, seppur senza guardarmi, mi ha sorriso fin da quando l'ho presa a scuola, e per tutto il tempo della presa. Quel sorriso, per me, è il sole».

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