

## Autism. Research, Economic and Governmental Intervention Plans

**Stefania Argenti\***

Laboratorio Athena, via Case Sparse, Italy USA

**\*Corresponding Author:** Stefania Argenti, Laboratorio Athena, via Case Sparse, Italy.

**Received:** May 14, 2019; **Published:** September 25, 2019

### Abstract

This article deals with autism, a condition that includes a series of Pervasive Disorders of Development, contained within the definition of Autism Spectrum Disorders (ASD). From the clinical viewpoint, these disorders are chronic and complex, etiology is unknown and decisive therapies do not exist.

Information and data, that will be employed, will concern networks participating in the research of the origin of this disease, early diagnosis and intervention procedures.

Global research operates in various areas, first in the genetic, biological and environmental.

Research groups, in particular the Seattle University team, that plays the role of coordinator of the world net research, interacting and allowing outcomes to convey in a single global database, are aimed towards discovering the largest number of factors responsible for disorders of the autistic-spectrum.

Through complex analysis of DNA, the introduction of new technologies and by observing and monitoring the psychophysical development of autistic children, scientists have made findings which will be outlined in the article, where methodologies for action and treatment, such as Applied Behavioural Analysis (ABA) and DENVER methods will also be analyzed.

Experience on the ground will be considered, putting into practice theories regarding the effectiveness of treatments.

Issues linked to research costs, to the budget related to training and treatment of personnel will be dealt with; particular importance will be given to the real economic capacity of governments to reconcile concrete studies and actions.

Finally, the importance of governments in intervention plans will be emphasized.

**Keywords:** Health Economics; Autism; Research and University; University Network

### Introduction

Autism is a neurodevelopmental disorder classified as Autism Spectrum Disorders ASD. Asperger Syndrome is the first level of autism. Aetiology is unknown. It is a serious lifelong disability, thus requiring integrated comprehensive community based support and services necessary to improve the quality of life for people with autism. In this aim, under the multidisciplinary and multi-agency approach, services should be widely rendered to provide access to healthcare services and educational agencies.

This biologically determined disorder of development makes its debut in the first 3 years of life. Children with autism have very serious language impairments, they show considerable difficulties in developing emotional and relational reciprocity with others and with the environment, they have limited interests and stereotypical and repetitive behaviours. There are however atypical aspects of the disorder, the characteristics of marked phenomenal divergence lead to the definition of autistic spectrum.

Autism disorders share the above mentioned traits, but they may have different variations from subject to subject, the common consequence is a disability characterized above all by a social deficit which is protracted throughout life.

Autism does not appear to have geographic or ethnic prevalence, and has been described in all the populations of the world with a gender prevalence, affecting more males with an incidence 3 - 4 times greater than in females [1]. It has no single cause, its origins are multifactorial, multiple genes and environmental factors, it is already established in the intrauterine life phase, the research carried out by the global scientific community is coordinated, linked and aimed towards the identification of causes and effective therapies.

### Autism and research fields

The world university research on autism, takes place on several fronts, in the genetic and environmental field; an innovative genetic mapping technique, called Array-Comparative Genomic Hybridization, is currently being used. This technique allows the identification of cancellations and DNA duplications with a precision five hundred times superior than a traditional chromosomal map. Results of a genetic research carried out by the Rome Biomedical Campus show that only 30% of the cases of autism has exclusively genetic origin, many other factors contribute in the remaining percentage. According to statistics from the US Center for Disease Control and Prevention of genetic detections, it is clear that every sixty-eight children born, one is autistic, a percentage which has increased compared to the past. A work published in the *New England Journal of Medicine* [2] claims that the disorder originates in pregnancy, this thesis is also supported by a group of researchers from the San Diego School of Medicine and by the Allen Institute for Brain Science in Seattle. The latter through examination of the brain tissue of 22 children, 11 healthy and 11 affected by autism who died between 2 and 15 years old, has discovered that the brain structure that forms before birth, in autistic children is different from that of healthy children.

In the former there are no genetic markers linked to brain development. The disorder therefore appears to be associated with a different prenatal development of the cerebral cortex. The outcomes obtained in this direction, have allowed the creation of an international network for the collection of brain tissue, the network called Autism Brain Net will be devoted to the acquisition, processing, storage and distribution of donations of brain tissue at the global level and within a decade it will become the reference point of institutions, associations and community of researchers and scientists working on human tissues in order to develop possible therapies in the treatment of the disorder. For the next few years Autism Brain Net will have \$ 7.5 million, available thanks to the University of California, the University of Texas, the Mount Sinai School of Medicine of New York, the University of Seattle, but the network will continue to grow including more universities and institutions.

Autism is therefore a disorder with a biological base linked to alterations of the cerebral cortex partly acquired partly due to genetic aspects. There is no gene of autism, but several genes can compete with each other as evidenced by a study published in the journal *Nature* [3]. The relationship between genes and anatomical abnormalities of the brain in autistic children is now well established. These molecular biology discoveries are increasing and reinforcing our knowledge about the biological basis of autism [4].

In the environmental field, a study published in the journal *Plos Computational Biology* of the Chicago University revealed that autism and intellectual disability are closely linked to the exposure of harmful environmental factors during fetal development [5]. Pregnancy has some periods in which the fetus is particularly vulnerable towards a series of substances such as plasticizer, pesticides, exhaust gas, mercury and lead. These elements, as demonstrated by the results of authoritative researches, alter the development of neuronal cells, compromising the correct brain growth of the fetus [5]. It is not yet possible to establish with certainty how much the interaction between environmental and genetic factors affects the onset of autism, a fact now acquired is on the contrary that both contribute to the establishment of it. The international research team has shifted its focus from psychology to genetics and to the environment, especially to inheritance. In Italy, in this area, the University of Sapienza in Rome and University of Parma participate in the international research on autism through the monitoring of individual cases and treatment and collecting data that are regularly entered into a global database.

### Treatment techniques

In addition to research, early identification of the disorder and diversified treatment techniques, are also important. The University of Seattle is in the avant-garde as regards research on intervention methodologies, in fact some of the most accredited methods in the

world for the treatment of autism come from years of behaviourist studies of the aforementioned American university. Many faculties of psychology world-wide train their own researchers in Seattle and Parma is one of these. After graduation, scholars return to their laboratories and by conducting common studies with territorial peculiarities, they provide the most complete information about the pathology. The team of American researchers at Carnegie Mellon University has found that in the context of early diagnosis, one of the most effective strategies is functional magnetic resonance imaging, which identifies anomalies of the cerebral cortex in early life stage, when there are still no obvious symptoms. Other means of early diagnosis are: the quality of crying – the cries of autistic children have some variations compared to the cries of healthy children - and the almost absence of eye contact in autistic children.

### The Denver method

The Denver model was promoted at the beginning of the 1980's by Sally Rogers of the University of Colorado Health Sciences Center. The central core of this method is the conceptualization or basic knowledge of autism. The families of autistic children are at the base of this methodology. It is a model based on the evolutionary approach and it consists in favouring the child's initiative, participation and motivation. The Denver method considers a hypothetical deficit of the imitative ability due to an underlying praxis disorder or to the lack of the ability to program the sequences of movement that would prevent the early settling of the synchrony and body coordination, thus leading to cornerstones in treatment.

It uses strategies such as, the inclusion of the child in coordinated and interactive social relationships throughout the day, which establish imitation and symbolic communication in order to start the transmission of experiences and social knowledge. In addition, intensive teaching is used to fill the void caused by learning disadvantages prior to therapeutic interventions. Finally, it uses the teaching of imitation, developing awareness of social interactions and reciprocity and teaching of the power of communication. These children must be taught what in their healthy peers is automatic and natural [6].

### The ABA method

In the late 1960's, Ivar Lovaas, psychologist and professor at the UCLA, started working with children affected by autism by using behavioural strategies. This method was developed on the basis of several years of research and intervention.

Aba is the acronym of "applied behavioural analysis", which is the systematic application of the behavioural principles identified by the science that studies behaviour and the laws that regulate it [7].

Aba is proposed as a practical technique for the modelling, implementation and evaluation of intervention programs. This methodology is based on the observation and recording of behaviour that provides the starting point for creating and implementing interventions for modifying inadequate behaviours and learning new skills.

One of the central principles of behaviourism is that of reinforcement. The frequency and the form of a given behaviour can be influenced by what happens before or after the behaviour itself. The principle of reinforcement and behavioural techniques, chaining, fading and shaping, etc. can be used to increase or reduce certain behaviours, to develop and consolidate new learnings.

This model consists of intensive educational intervention of about 40 hours per week, carried out by operators with specialized training and under the supervision of behavioural psychologists. The 6-hour daily intervention is also carried out at home and is initially focused on the development of communication skills, imitation and play. The child is then gradually integrated into the school with the necessary support. Research data shows that people with autism can benefit significantly from ABA educational interventions and it is suitable for every age group [8].

There are several factors that influence it: the effectiveness and precocity of intervention (according to literature it emerges that ABA is more effective if started within the four years of life) the intensity of the intervention and involvement of the family. When correctly applied, this method has proven to be effective in many cases (but not in all), in which children have achieved and subsequently maintained standard scores in different cognitive, linguistic and social functioning tests [9].

There are numerous implications in family life as the whole family is involved in the educational process especially the parents who are responsible for the maintenance and generalization of new skills acquired by the child; in particular during the first two years of intervention in which the program is conducted mainly at home. The family must be willing to transform at least one room into a classroom and an educational environment and to give free access to psychologists for the session with the child.

Expenses are significant, they include the payment of supervisor and educators, the cost of teaching materials and reach 30,000 euros per year [10].

Data available on the study of this method, report attention on the two fundamental variables, duration and intensity of the intervention such as effect modifiers, however there are no data to quantitatively estimate the unclear role of other issues such as those linked to the subject or topics of an unknown type potentially capable of modifying the result obtained. To date there are no definitive figures available to support the effectiveness of the ABA model compared to others such as the Denver one. Research is therefore oriented not only on the identification of the origin of the disorder, but also on the consolidation of existing techniques and on the formulation of new methodologies.

According to the recommendations of the ISS guidelines, since there is a large individual variability in the outcomes obtained from the intensive behavioural ABA programs, it is necessary to carry out a clinical case specific evaluation to monitor the effectiveness of the intervention in the individual child i.e. if and to what extent the expected results are reached.

### Some cases of species

The implementation of the Denver method, entails an adequate training of both professionals and families of autistics. This requires increasing resource flows that families cannot always afford.

The method that in my experience proved to be the most effective is undoubtedly the ABA method. If integrated with a targeted psychomotor therapy and accompanied by speech therapy for people with cognitive disorders, in the long run it allows good results both in language and in coordination of body movements.

Two cases can attest my professional opinion.

- **Luca A:** At the age of eight did not emit any sound, after a year of treatment, through reinforcements and rewards, he managed to express himself with sentence-words; after about two years his imitative language is almost complete. Unfortunately, due to severe dyspraxia, his physical coordination did not have the same language development.
- **Anna B:** With the ABA method, through representative icons, managed to lift herself from a kneeling position to the erect one without any help and from a medium-high dyspraxia level she passed to a medium one.

In conclusion it can be said that there is no panacea, but with tailored and diversified adjustments and adaptations of established methods it is possible to achieve appreciable results.

### The impact of autism on individuals, families and society

Autism is increasing all over the world. It is estimated that one in 160 people is autistic. The number of families involved is high; it is now an epidemic and a social emergency that requires targeted and massive intervention, both in terms of strengthening research and economic support for families, health and social services and schools. The task of governments is to allocate economic resources and to outline capillary action programs on the territories, thus supporting the work of private associations and organizations already existing in Europe and all over the world. A functional global psycho-social support network is therefore important, as it is already the case for the research which connects the institutions of each state dealing with the problem allowing a reciprocal exchange of information. This would help to prevent the social consequences of this problem since the fallout that this disease has on the lives of the autistic on their families and on society is a major issue.

Autism spectrum disorders make human beings unaware of their rights and often expose them to violence and abuse.

From childhood to adulthood the autistic is completely marginalized. For example, at school children are bullied because of their uncoordinated movements and because of stereotypes, so school inclusion and rights of the disabled are not guaranteed [11].

The delay in diagnosis by the National Health Services due to the lack of specialized staff, the shortage of funds, trigger a chain mechanism that aggravates the conditions of those suffering from autism, generating other disorders such as depression, which also affects family members, causing sense of unease, anguish, impotence and frustration [2]. The family represents one of the pillars of society, autism puts it to the test; mothers have to stop working to take care of their children, sometimes in the same family there are two autistic siblings, parents fears for the future of their children when they will no longer be able to take care of them causing a sense of doom [12]. The teacher's problem is the inability to manage the class and the children who fall into the autism spectrum, and administrators do not give answers to teachers because they cannot find funds and they try to deal with the obstacles that occur in an unorganized and inefficient way without getting anything.

### Government intervention plans and costs

It is evident that the problem is political-economic in nature and as such, must be tackled and resolved by Governments.

Urgent measures that must be taken in the social sphere by the EU related to autism were discussed and an economic-social action plan was drawn up and implemented, but it has been achieved only by a few countries to date [12].

Addressing the problem means keeping in mind three fundamental aspects: social, economic and personal health, affective-emotional and relational of all the subjects involved. The peculiarity of the disorder compromises the adaptability and resilience of social relationships.

### Terms of intervention are the following:

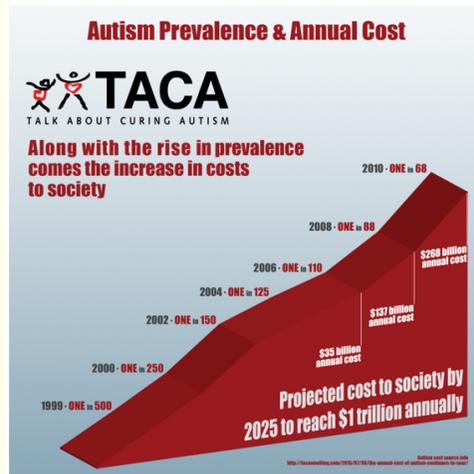
#### Organization of the evaluation services

- Management and coordination of the interventions that should be guaranteed in the territorial services by multidisciplinary local teams, specialized and made up of professionals as recommended by the National Institute for Health and Care Excellence guidelines on autism;
- Professionals and health and social workers, should receive an accurate training in order to acquire proper skills in dealing with maladaptive behaviour [13];
- Sustenance for families through practical supports.

### Autism occurrence

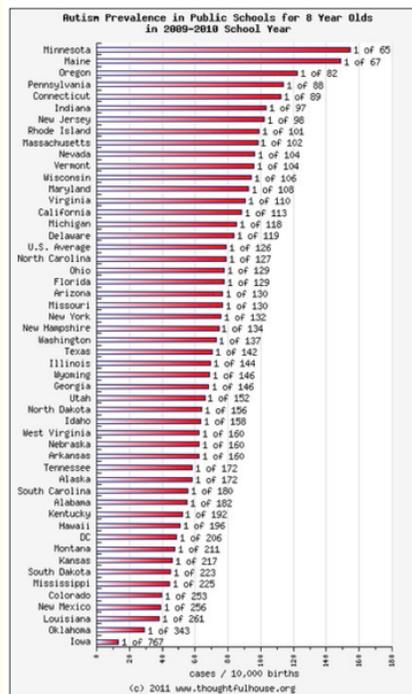
- New Prevalence Numbers for 2014: 1 in 45 US Children have autism. November 13, 2015.
- Revised Estimates of the Cost of the Autism Epidemic (July 2015).
- New Rate of Autism 1 in 68 (March 2014).
- The complete Disease Control and Prevention (CDC) report "Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010" dated March 28, 2014.
- New Parent survey shows autism affects 1 in every 50 U.S. children. Will this new number be used by the Centers for Disease Control? (March 2013).
- Paediatrics Reports - One in 91 Children in the United States Has Autism (October 2009).
- CDC: One in 110 American Children has Autism (December 2009).

- **AUTISM OCCURRENCE:** One in every 68 children in the US has autism (read CDC March 2014 Study). It is estimated that almost 2 million individuals in the U.S. has autism. (Note: This number and the following statistics below do NOT include: Pervasive Developmental Disorder, Asperger’s and other spectrum disorders.) These statistics are endorsed by the Centers for Disease Control and Prevention (CDC), American Academy of Pediatrics, and other federal agencies.



**Chart 1: Autism Prevalence and Annual Cost.**

Source: Autism Society 2010 Maryland USA in [https://en.wikipedia.org/wiki/Autism\\_Society\\_of\\_America](https://en.wikipedia.org/wiki/Autism_Society_of_America).



**Chart 2: Autism Prevalence in Public Schools in 2009-2010.**

Source: Autism Society 2010 Maryland USA in [http://en.wikipedia.org/wiki/Autism\\_Society\\_of\\_America](http://en.wikipedia.org/wiki/Autism_Society_of_America).

### The contribution of Italy on autism

According to Ansa data, these days in Italy there are among 300.000 and 500.000 autistic people and their number are growing and growing.

On 5th August 2015, Italian Government approved a Law on Autism [14], came into effect on 12 September 2015 that provides with for the alignment to the international guides. The law promotes the development of research programs and therapeutic procedures to curb autism, but the funds allocated in the National Budget to seriously fight the problem remain stationary, not allowing any improvement.

On the contrary, in some regions like Emilia Romagna, there is more awareness of the issue, and local institutions try to gather funds with the aim to intervene at an early stadium of the disease.

The collaboration between University of Parma and the regional government has led to great results.

ABA, TICE (techniques for competences of developmental teaching) centers, where a series of services such as study aid, reinforcing, expertise, supervision and contextualized treatment are provided, have been established.

With the aim to gather funds, particular attention is reserved to the scientific supervision, to the creation of a business plan and to the building of a partnership with territorial entities.

In Emilia Romagna, these centers along with the university research, are working together in synergy with the global network autism experts, such as US universities, rendering advanced services in their territory partly financed by public bodies.

Emilia Romagna has approved a regional law [15] that provides with the creation of a territorial fund aimed at finding a cure for autism, through public and private financing.

### The best practices: The Scottish Strategy for autism [16]

What will follow is an example of how a government, that of Scotland, has put in place an effective, economic-health strategy to cope successfully with autism.

Autism has been the subject of a number of initiatives over the past decade. Considerable efforts have been made to improve diagnosis and assessment, to create consistent service standards, providing longer-term underpinnings for appropriate research and training opportunities and to match resources to that need. The Scottish Government, working in partnership with the Convention of Scottish Local Authorities, has spoken to individuals on the spectrum and their families. What changes are needed? We will continue to work in this way. A draft autism strategy was widely discussed by professionals of all disciplines involved in the provision of public services.

### Working group chairs

Each work group is chaired by a member of the Governance Group. Workgroups are responsible for delivering the guidance, direction and relevant expertise in the development and delivery of the priority work plans.

Work groups have the authority to make decisions regarding the approach adopted to deliver work plans.

Workers have been chosen from a wide range of stakeholders in the wider autism community, including autistic people, careers, services and supports providers, academics and others, to enable collective thinking and to work for the Group as a whole.

The Governance Group is responsible for providing assurance to Scottish Government. The Governance Group will provide strategic leadership to the delivery of the strategy's recommendations for improving outcomes for individuals and families living with autism. Results show a better integration and inclusion of children at school along with a better management of the autistics by families.

### Conclusions

Autism is a complex phenomenon that requires measures on several fronts, the possibility of success is closely linked to research both with regard to its origin and with regard to treatment methods. Currently all the continents are included in this scientific enterprise, but unfortunately we do not have the data of all the states. This is due to different causes: non-existent governments, corrupt governments and wars. If scientists could have more information, they would have access to new elements to intervene in the treatment of autism that is growing like wildfire in every geographical area. However, the worldwide research network has succeeded in taking giant steps in outlining the guidelines and in defining the intervention protocol, some governments are moving ahead and are including funding for autism in their budgets; associations, corporations and universities in synergy work in a constant and profitable manner.

The structure of the world research network has proved to be a success. It started from US universities of Chicago, UCLA and Texas and Chicago University and has spread all over the world.

The University Psychology faculties, monitoring the work carried out by ABA centers linked to them, gather information both on the response to therapy by the autistics and on the efficiency of work of psychologists.

The University faculties of Biology and Medicine are linked on a global scale and provide generic data, helping to define the liaisons of genes responsible for autism.

The results converge in a global data bank, with the scope of improving therapies and standardizing interventions.

In the therapeutic field, in Italy the University of Parma is role model and provides a very good example of interaction with local public authorities and world Universities.

Problems related to collaboration and financing by national governments are being experienced, while the research continues reaching many objectives; legislation is still not adequate and therefore it does not provide the possibility to actually support people suffering from autism and their families.

### Bibliography

1. Scottish intercollegiate guidelines network sign. Edinburgh (2007).
2. Jeffrey P Baker. "Autism at 70 - Redrawing the Boundaries". *The New England Journal of Medicine* 369 (2013): 1089-1091.
3. Simon Foundation International meeting for autism research (2012).
4. Lab of Developmental Cognitive Neuroscience Autism Research Center of Excellence Boston University School of Medicine (2013).
5. Plos Computational Biology Chicago University (2010).
6. Hawkins RP, *et al.* "Behavior therapy in the home amelioration of problem parent-child relations with the parents in a therapeutic role". *Journal of Experimental Child Psychology* 4.1 (1996): 99-107.
7. Lovaas I. "Teaching developmentally delayed children". Pro-ed, New York (1981).
8. Richman S. "Raising, A child with autism, a guide to applied behavior analysis for parents". Jessica Kingsley Publishers, London (2001).
9. Maurice C. "Behavioral intervention for young children with autism". Pro-Ed, New York (1996).
10. Mondial Health Organization (2013).
11. UNO Official Declaration on the rights of people with disability (2016).
12. M-Media Lab exploratory, cooperative of work for people with Asperger syndrome, Lem Libraria- Lem. Coop. (2016).

13. Cartabellotta Antonino. Management Measures of Autism, Evidence (2014).
14. Government and Parliament, Autism Law, published in Official Journal (2018).
15. Emilia Romagna, Italia, Legislative Assembly (2016).
16. The Scottish Strategy for Autism (2013).

**Volume 8 Issue 10 October 2019**

**© All rights reserved by Cusmà Piccione R and Andreotti A.**