Review Article

Autism: A Generation at Threat

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Abstract

A generation of children is at risk as the incidence of autism increases. No consensus exists on the causes of autism or its treatment. A wide range of potential factors such as genetics, vaccines, and environmental toxins is being explored. Some clinicians offer a combination of behavioral, educational, and pharmaceutical treatments, whereas allied health professionals stress diet, biomedical interventions, and chelation. With a lack of an organized approach to diagnosis and treatment and a lack of trained professionals, children are not receiving timely interventions. Curing autism has to be made a national priority. National programs should conduct research, standardize treatments, and offer public and professional education.

Key words: Autism, autism spectrum disorders, health planning.

Purpose

The incidence of autism spectrum disorders (ASD) is becoming an epidemic. This phenomenon, not unique to the United States or Europe, is fast emerging as a worldwide problem. This paper reviews the gains made and obstacles faced in the diagnosis and treatment of ASD and proposes a comprehensive plan to deal with this phenomenon.

Autism Spectrum Disorders

Autism spectrum disorders are neurobiological developmental disabilities that generally appear before the age of 3. Autism spectrum disorders impact the normal development of the brain in the areas of social interaction, communication skills, and cognitive function. Individuals with ASD typically have difficulties in verbal and nonverbal communication, social interactions, and leisure or play activities. Individuals with ASD often suffer from numerous physical ailments, which may include, in part, allergies, asthma, immune system dysfunction, mitochondrial disease or disorders, epilepsy, digestive disorders, persistent and recurrent infections, feeding disorders, sensory integration dysfunction, sleeping disorders. Autism is diagnosed four times more often in boys than in girls. Its prevalence is not affected by race, region, or socioeconomic status.1

Autism is diagnosed based on clinical observations and testing by professionals using one or more standardized tests. Professionals most likely to diagnose autism are neuropsychologists, psychologists, psychiatrists, developmental pediatricians, and school psychologists.2

Autism is an Epidemic

Autism spectrum disorders are the fastest growing neurobiological abnormalities worldwide.3

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According to the Centers for Disease Control and Prevention (CDC), the prevalence of ASD in the United States is 1 in 150. A more recent statistical analysis suggests that in Minnesota as many as 1 in every 81 children has autism. This variance may be explained by differences in classification or an increased incidence in the last several years. A study in the United Kingdom estimates that as many as 1 in 38 boys has some form of autism. As many as 1.5 million Americans today are believed to have some form of autism, and this number is on the rise. Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a startling rate of 10-17 percent per year. At this rate, the American Society of Autism estimates that the number of people with autism could reach 4 million in the United States in the next decade.

**Theories of Causation**

From the early 1950s and into the 1970s, it was widely believed that the mothers of children with autism neglected their children and were not loving enough, which in turn caused the children to regress into a world of their own. These mothers were labeled “refrigerator mothers.” Thanks to Dr. Bernard Rimland, himself the parent of a child with autism, this theory has been discredited.

However, more than 50 years later, there still is no consensus on the causes of autism. The etiological theories range from genetics, vaccines, environmental toxins, immune deficiencies, and more. Many hypothesize that it is a combination of factors, for example, a genetic susceptibility to autism triggered by an environmental insult.

**Genetics**

There are many in the scientific community who believe that there is a strong genetic component or predisposition to ASD. It is important to note that in the past 10 years of looking for the “autism gene,” none has been found. This has led many researchers to believe that there has to be a trigger to turn on the gene and hence cause autism. According to officials at the U.S. National Institutes of Health (NIH), while there is most likely a genetic predisposition, there must also be an environmental component to autism. The rapid rise in the rate of autism over the last 15 years cannot be attributed solely to genetics. However, there are some clues in recent genetic research. A 2008 study found genetic changes on chromosome 16 in the children and families of children with autism. The incidence of these specific genetic abnormalities was much higher in these families compared to general population, though still representing a relatively small, though significant, number of cases. The possibility of a genetic defect in the mitochondria of the cell as a predisposing factor has recently been recognized.

**Environmental Toxins**

Parent advocacy groups, activists, and some members of the scientific community support the theory that environmental triggers and vaccines may cause some cases of autism. The Autism Research Institute (ARI) believes environmental factors — including unprecedented exposure to toxic substances and overvaccination of infants and young children — are the key factors triggering this devastating epidemic. According to the National Autism Association (NAA), a parent advocacy group, “Autism is no longer considered a heritable, genetic disorder. It is an environmentally triggered, therefore preventable and treatable disease. Environmental research holds the key to finding the cause and developing effective treatments for those affected.”

A recent study revealed that autism spectrum disorders may result from a combination of genetic/biochemical susceptibilities in the form of a reduced ability to excrete mercury and/or increased environmental exposure to mercury at key developmental times.

Autism may begin when early environmental, infectious or autoimmune insults trigger an immune response that increases oxidative stress on the brain. Conceptualized in another way, the autism spectrum disorders are a combination of neurologic, immune system and gastrointestinal reactions and expressions of the impact of environmental toxins on genetically susceptible infants and children. Studies have associated autism and/or other neurodevelopmental disorders with exposure to mercury, lead, alcohol, polychlorinated biphenyls (PCBs), polybrominated diphenyl ethers (PBDEs), manganese, arsenic, solvents, polycyclic aromatic hydrocarbons (PAHs), pesticides, brominated flame retardants, plastics and nicotine/environmental smoke. Phthalates, which are known to interfere with hormone (steroids) synthesis, are used in products such...
as soft vinyl plastic toys, shampoos, hairsprays, nail polish, waxed cheese wraps, perfumes and deodorants, new cars, and pharmaceuticals. Styrofoam, a polymer of styrene, is neurotoxic, and Teflon, classified as perfluorooctanoic acid (PFOA), is a likely carcinogen and can cause immune system damage. Tens of thousands of babies per year in the United States are born with neurodevelopmental disorders due to fetal exposure to mercury.

**Vaccines**

A link between autism and vaccines has not been firmly proved or disproved, though there is mounting evidence of a connection. In March 2008, a panel of medical evaluators concluded that a young American girl, Hannah Poling, had been injured by vaccines. The federal government vaccine court, with no formal hearing, conceded that the nine vaccines Hannah received significantly aggravated an underlying medical condition, mitochondrial dysfunction, a condition of impaired cellular functioning. This predisposed Hannah “to deficits in cellular energy metabolism and manifested as a regressive encephalopathy with features of autism spectrum disorder”. Mercury from the thimerosal in vaccines has been linked to autism and other neurodevelopmental disorders. Analysis of a previously unexamined database maintained by the CDC strongly suggests that exposure to thimerosal through hepatitis B vaccines is associated with neurodevelopmental disorders, including autism. Thimerosal is still used in vaccines in third world countries and in flu vaccines and in trace amounts in other vaccines in the United States. Moreover, for several years after the 1999 recommendation that thimerosal be removed from childhood vaccines, some mercury-containing vials remained available on the shelves and were utilized until they expired. While some studies have concluded no link between vaccines and autism, many of these studies have been criticized. For example, in September 2008, a study published by Columbia University and supported by the CDC and NIH, showed no link between the measles virus vaccine and autism. Many autism associations and advocates for safe vaccines have challenged the results of this study on the basis of the flaws in the design of the study, its assumptions, and its small sample size. They are advocating for research to be done on vaccinated vs. nonvaccinated children.

While the debate on causes of autism rages between concerned parents, the medical community, CDC, the U.S. Food and Drug Administration (FDA), the pharmaceutical industry and scientists, “cure” is becoming an elusive goal.

**Treating Autism**

There is no consensus on the treatment of ASD. Mainstream medical practitioners stress a combination of behavioral therapies and pharmaceutical treatments. Allied professionals stress special dietary regimens, biomedical intervention, and chelation therapies.

Pediatricians in mainstream medicine advocate educational interventions such as application of applied behavior analysis (ABA), application of developmental models, structured teaching, social skills instruction, speech therapy, occupational therapy and sensory integration therapy combined with medical management for conditions associated with ASD.

The Autism Research Institute (ARI) registry lists physicians and other medical practitioners who provide biomedically based treatment for children and adults with autism. These practitioners are referred to as Defeat Autism Now! practitioners. The Defeat Autism Now! philosophy involves treating the underlying causes of the symptoms of autism, based on medical testing, scientific research, and clinical experience, with an emphasis on nutritional interventions. Defeat Autism Now! treatments are child-specific and may include determining and treating food allergies and sensitivities and improving diet (through the use of diets such as the gluten-free casein-free diet, specific carbohydrate diet, and other dietary interventions), vitamin/mineral supplements such as methylcobalamin (MB12) injections, high-dose vitamin B6 and magnesium, essential fatty acids and amino acids, gut treatments such as antifungals, parasite treatments, probiotics and digestive enzymes, melatonin to address sleep issues, thyroid treatment (many children with ASD exhibit hypothyroidism), treatments to improve the sulfation pathways, treating viral issues, glutathione, chelation, and treating systemic inflammation and immune system regulation issues.

Biomedical treatment is suggested as a supplement to the therapies recommended by more mainstream practitioners, not a replacement. Each child’s
comprehensive program of biomedical treatments, therapies, and behavioral and educational interventions is unique and determined by a child’s individual needs. In addition, families are using other therapies such as Verbal Behavior Analysis (VBA), Developmental, Individual-Difference, Relationship-Based, or “DIR®” and Treatment and Education of Autistic and Related Communication-handicapped Children (TEACCH).

Funding for Autism

In the United States, autism research has had limited funding. In 2005 the NIH dedicated only 0.3 percent of its budget to autism. Autism is still very far behind in private funding. Leukemia affects 1 in every 25,000 and has $300 million in private funding. Pediatric AIDS affects 1 in 8000 and has $394 million in private funding. Autism affects 1 in 150 and has only $15 million in private funding. The funding for education of children with ASD is even less.

Moreover, in most states, health insurance reimbursement for the treatment of autism is extremely limited or nonexistent. Generally, insurance plans classify autism as a psychiatric disorder. Whether it is for treatment of a physiological condition or for a recognized behavioral intervention, insurers use the autism “mental health” exclusion to avoid paying claims for services such as ABA and other interventional therapies such as speech, occupational, and physical therapy, as well as diagnostic tests. Pressured by autism advocacy groups, some states now mandate some coverage for treatments such as ABA. Some states prohibit discrimination in health insurance coverage for autism. Only 17 states have insurance laws relating to autism coverage (California, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Montana, New Hampshire, New Jersey, New York, Tennessee, and Virginia). Of these, 10 require coverage for autism through their laws mandating coverage for mental illness (California, Illinois, Iowa, Kansas, Louisiana, Maine, Montana, New Hampshire, New Jersey, and Virginia). The other six states have specific laws regarding insurance coverage for autism (Georgia, Indiana, Kentucky, Maryland, New York, and Tennessee).” Most recently, Oregon gained full parity this year.

The federal government also is taking some action with respect to autism. The Combating Autism Act of 2006 allocated approximately $950 million in spending on autism over 5 years, with only $90 million devoted to surveillance and research. The bill did not include the provisions that would have specified funding for investigating possible environmental causes. It appropriated $210 million for education, early detection, and intervention, over a 5-year period. However, federal funding for ASD has not increased to the levels authorized by the Act and there have been recent attempts to remove funding for important research from the Act.

President Barack Obama, during his 2008 presidential campaign, pledged to increase federal ASD funding for research, treatment, screenings, public awareness, and support services to $1 billion annually by the end of his first term in office. Additionally, President Obama committed to bringing autism insurance reform to the entire nation saying his administration “will mandate insurance coverage of autism treatment and will also continue to work with parents, physicians, providers, researchers, and schools to create opportunities and effective solutions for people with ASD.” While still a U.S. Senator, President Obama drafted legislation entitled “Autism Treatment Acceleration Act of 2008”, which includes broad-based federal autism insurance reform.

Impact on Families

With an alarming increase in new cases of autism spectrum disorders, and with a dearth of appropriately trained diagnosticians, caregivers, therapists, and educators, the demand for care and treatment now far exceeds the supply of qualified providers.

When families suspect their child may have autism, they sometimes wait for over 6 months to even see a professional to establish a diagnosis. Learning that their child has autism is devastating to the parents. This already overwhelming experience is compounded when families have to wait months to obtain appropriate services to help their children, who benefit greatly from the earliest and most intensive intervention possible.

Children under 3 often face a long wait for evaluation by their local early intervention program and then another wait to obtain recommended services. Similarly, parents of school-aged children often find that obtaining an appropriate classroom placement and therapeutic services for their child with ASD is difficult, and in some areas, virtually impossible. A
school district should establish an individualized education plan (IEP) for a child. Unfortunately, the scope and degree of intervention offered by the district often is far below what is appropriate for the child. A child for whom 40 hours of ABA therapy a week is a appropriate may end up receiving no more than 10 hours and sometimes none at all. Frustrated, and seeing their child making no progress — or even worse, watching their child regress — parents reach out to private sources to supplement the school services, only to be confronted with astronomical costs and long waiting lists for appropriate private programs. Assuming a family can find an appropriate private placement for their child, the parents have to pay the cost for private schooling (some programs cost approximately $100,000 a year) and then seek reimbursement from their school district, one year at a time. These costs are straining families both emotionally and financially.

The financial burden and emotional stress of autism is threatening the family unit. Not only are marriages threatened, there can be household tension as parents try to balance the needs of the child with autism and those of the other children in the family. The stress that siblings encounter also cannot be minimized. Younger siblings find themselves in a reverse role of big brother or big sister; siblings may compete for parents’ attention, or find themselves in a socially awkward situation, having to explain their sibling’s unusual behavior to their friends. If there is only one sibling, he or she may feel at a disadvantage for not having a playmate in the house or feel pressured when expected to make room and allowances for the sibling with autism. As siblings get older they may be concerned about future care when the parents no longer can care for the sibling with autism.38

Children with autism are at risk of hurting themselves. The leading causes for concern are children and adults who run away or wander from parents and care providers (known as elopement). Wandering children and adults with autism are often attracted to water sources, and drowning is a leading cause of death for children and adults with autism.39 Some children with autism also engage in self-injurious behavior — such as head-banging — and must be monitored carefully to avoid serious harm.

Many children on the autism spectrum are now entering their teens. Some are adults, and very quickly, the demographics of people with autism will shift. Families are finding a lack of resources to take care of adults with autism. Neither government agencies nor insurance companies are prepared.

So what are parents — frustrated by the waiting and the lack of services and concerned about their family’s future and the future of their child with autism — to do? They do what we all do when looking for answers. They turn to the internet. They Google “autism”. Hundreds and thousands of links show up. The list of treatments offered is endless. How do they navigate this vast amount of information? How do they assess what is right for their child? To say that parents are overwhelmed is an understatement, and they often receive little support in navigating this information.

In the absence of scientific research, mainstream medicine has been cautious in its approach to alternative treatments. Families that prove or disprove any given therapy but families hear the clock ticking. Far too many families have been told by their child’s physician that it is futile to try to treat autism, offering little in the way of intervention or hope. In the absence of standardized treatment, families feel abandoned and lost and many families seek out alternate treatments. Some families have had incredible results with these treatments, and there are many reputable providers. Unfortunately, many other families have fallen prey to charlatans promising miracle cures and have exhausted their resources in the pursuit of a cure.

**While A Cure Is Being Sought**

To draw attention to this circumstance, parents in the United States have engaged in advocacy, awareness, and activism. Parent-led initiatives have gained momentum. Parents are the drivers for advocacy, activism, support groups, lobbying, alternative medicine, and critical review of studies being conducted. Celebrities such as Oprah Winfrey and Jenny McCarthy have been instrumental in raising awareness. Affected families and concerned citizens have taken the lead in forming national associations with mandates that include research, philanthropy, awareness and education, support, networking, advocacy and media engagement. Some of these associations have established local chapters, allowing them to respond on many levels. Many also hold
national conferences that have become the forum for bringing hope and knowledge to families (Table 1).

It was through the drive led by affected families that the United Nations declared April 2, 2008, World Autism Awareness Day. World Autism Awareness Day was also observed on April 2, 2009.

Responding to the special needs of affected families, the legal profession has developed a niche in advocating for the special education rights of children with autism. All this has not escaped the notice of the media, and major networks have aired special programs for autism awareness. Mothers, therapists, nutritionists, and scientists are publishing books on parental education, diet, play therapy, and biomedical intervention. Periodicals and journals can now be seen on newstands. A new market has emerged to provide tools and toys to aid speech, play, sensory integration, and social skills. Documentaries, videos, blogs, listserves, and podcasts have become the medium for communication and dialogue.

Philanthropists are raising funds through special drives. Legislators are responding, and there is a movement to increase the funding for research and special education across the nation. As a consequence, autism is now being recognized as an epidemic.

The vaccine theory remains unresolved and controversial. Advocates and activists are making the case for “safe vaccines” which do not contain mercury, aluminum, and other potentially harmful ingredients. They also call for individually-customized vaccination schedules, not a “one-size-fits-all” schedule. In the face of demands to vaccinate their children on a one-size-fits-all schedule, families and advocates are pushing for the option of religious exemption or conscientious/philosophical objection to vaccinating their children. Some states have passed legislation to permit these exemptions, which has raised concerns in the medical and pharmaceutical communities, as well as governmental agencies.

**Developing a National Action Plan**

A national action plan must confront some key issues. How do parents cope with this phenomenon? How does the medical community respond? What are the health policy considerations? What are the legal issues? What is the role of government, philanthropists, scientists, educators, advocates? How does the community at large respond? The goals of the plan should aim at research directed towards prevention and cure, treatment, and education.

Pediatricians should screen infants and toddlers for autism, with established screening guidelines such as CHAT, M-CHAT, CAST.1 Laboratory facilities and diagnostic capability for testing mercury and other toxicity levels, yeast infections, leaky gut syndrome, food allergies and other conditions would have to be in place.

Mechanisms to license and certify practitioners (therapists, clinicians, special education teachers, nutritionists, etc.) should be established to prevent opportunism. Biomedical treatments within practice guidelines and in accordance with the type of disorder should be approved. Private and public health insurance underwriting and coverage policies should facilitate access to approved screening and treatment providers.

Conventional medicine currently supports early

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**Table 1. National associations addressing autism and organizations providing information and resources.**

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<th>Organization</th>
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<td>Autism Society of America</td>
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<td>Autism Speaks</td>
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<td>Autism United</td>
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<td>Talk About Curing Autism</td>
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<td>Safe Minds</td>
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<td>Autism One</td>
<td>autismone.org</td>
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<td>Generation Rescue</td>
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<td>Unlocking Autism</td>
<td>unlockingautism.org</td>
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<td>Autism Research Institute</td>
<td>autism.com</td>
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<tr>
<td>The Sibling Support Project</td>
<td>siblingsupport.org</td>
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<td>Autism Speaks</td>
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...disciplinary forum (clinician, therapists) with the parent at regularly scheduled intervals.

It is also necessary to adapt school systems to meet the needs of children with ASD. Schools should be equipped to recognize symptoms of autism and conduct the appropriate evaluation if a child has not been evaluated before entering school or if symptoms of autism manifest at a later age. Students requiring intervention should be referred for special education within the school system. Special education teachers and psychologists, trained and certified in autism, should staff these classes. ABA and other educational models, occupational, speech, physical therapy, and sensory integration should be integrated into the school curriculum, and a program should be developed based on a child's particular needs. Goal setting and evaluation should be conducted at pre-determined intervals.

The school-based system would be extended into the home for off-hour educational therapy and related services such as occupational therapy, speech therapy, sensory integration therapy, and social skills therapy.

To support the aforementioned diagnostic and treatment programs, a cadre of qualified professionals should be cultivated, based on the expected demand for services. An educational program for therapists (for example, ABA, PT, OT, Speech) should be established to create and maintain a critical mass of professionals. Specialty training programs for clinicians should be established, either independently or in collaboration with existing universities.

It is also important to educate parents on recognizing the symptoms of autism, knowing when, where, and how to access care, and on caring for children with autism. Regularly scheduled workshops, seminars, or home-based education are all alternatives to be pursued. Parents should be trained on managing the symptoms of autism (behavior and gastrointestinal issues), play therapy, diet, safety, sibling rivalry, as well as extending the components of the child's educational and therapeutic program into the family's everyday life and activities. Parents should be provided with tools such as flash cards and play equipment to facilitate successful integration of the program into their home life. Parental education will empower the parents to help their child, knowing that they are supported in doing so.

Recreational facilities, which account for autistic
children’s sensory and motor skill limitations, thus providing them a safe space to play, should be made available. Parent support groups and resource centers can provide families a forum for networking, sharing experiences, learning from one another, building resources, and creating an extended family. Sibling support groups can provide a setting for peer support groups for siblings of children with autism. The goal of these groups would be to provide information opportunities for brothers and sisters, and increase parents’ and providers’ understanding of sibling issues. Workshops, listservs, and web sites would be established for communication and sharing of information.

Counseling services should account for ASDs in marriage counseling, parental counseling, child behavior issues, conditions arising from autistic care’s isolation, grief, and concerns over the future, financial planning, sibling issues such as explaining autism, relationship building, handling their stress from embarrassment, frustration, victimization, special demands, and grandparent counseling, to define their role in easing the burden of their children as parents.

To facilitate access, directories of professionals and allied health professionals that enable the parents to access providers, schools, and community programs should be created and distributed widely.

Steps should be taken to ensure that the market makes available items such as casein-free, gluten-free, organic foods, educational tools such as flash cards, games and toys that lend themselves to therapy and sensory and motor issues and educational material for families, caregivers and educators.

Media awareness campaigns should be conducted, geared towards sensitizing the public as well as educating families on recognizing the signs and symptoms of autism. Role models with success stories should be publicized through the media, support groups, associations, with the purpose of inspiring hope. Programs such as Mothers-helping-Mothers and Rescue Angels should be institutionalized. Rosters of volunteer parents should be maintained and matched with families looking for guidance.

To improve safety, neighborhood watch programs for assuring the safety of children should be developed. Law enforcement agencies should be educated on how children with autism behave and react, enabling them to effectively manage a child with autism in an emergency. Families should register their child with law enforcement agencies. Families should enhance home security systems to prevent elopement. Families should inform neighbors about their child’s autism to maximize the child’s safety in the event of elopement. Autism emergency contact handouts should be developed. Autistic children should have identification tags. Vehicles with children with autism on board should have a notice. Finally, swimming classes for children with autism should be regularly held.

Conclusions

The action plan proposed is ambitious in its scope. It involves every segment of society. This builds synergy and yields the most promising results. This initiative should be made a national priority and be undertaken with speed. Time is of the essence. A future generation is at stake.

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