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ANNOUNCEMENT

The International Association for Gender-Specific Medicine

Marianne J. Legato, Karin Schenck-Gustafsson, and Vera Regitz-Zagrosek

69

EDITORIAL

Balancing the Three-Legged Stool: Which Faculty Are Most Important in Our Academic Medical Centers?

Marianne J. Legato, Editor-in-Chief

71

LAW, ETHICS, AND GENDER

An Update on Autism: Science, Gender, and the Law

Jane J. Bartley

73

CSD GRAND ROUNDS

Why Women Live Longer Than Men: Sex Differences in Longevity

Steven N. Austad

79

REVIEW ARTICLE

Gender Differences in Depression and Response to Psychotropic Medication

Jack M. Gorman

93

ORIGINAL RESEARCH

Risk Factors for Fractures in Older Men and Women: The Leisure World Cohort Study

Stuart C. White, Kathryn A. Atchison, Jeffrey A. Gornbein, Aurelia Nattiv, Annlia Paganini-Hill, and Susan K. Service

110

Quality of Life with Vitiligo: Comparison of Male and Female Muslim Patients in Iran

Leili Borimnejad, Zohreh Parsa Yekta, Alireza Nikbakht-Nasrabadi, and Alireza Firooz

124

CONSENSUS STATEMENT

Gender-Specific Care of the Patient with Diabetes: Review and Recommendations

Marianne J. Legato, Andrea Gelzer, Robin Goland, Susana A. Ebner, Sabitha Rajan, Victor Villagra, and Mark Kosowski; The Writing Group for The Partnership for Gender-Specific Medicine

131

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Law, Ethics, and Gender

An Update on Autism: Science, Gender, and the Law

Jane J. Bartley, Esq

Shook, Hardy & Bacon, LLP, Kansas City, Missouri

ABSTRACT

Autism is the fastest-growing developmental disability today, affecting boys more than girls at a rate of 4 to 1. Research is currently under way to identify possible genetic implications and to develop appropriate treatments. Early intervention is recommended, but the cost of these therapies is high and often not covered by insurance policies. Families who turn to their public school district for assistance generally find that schools are insufficiently funded to meet the needs of children with autism, prompting parents to use the courts to obtain proper care and treatment. In several states, legislation is being introduced to require insurers to cover the cost of services or to provide vouchers to families for such services. On the national level, the Combating Autism Act of 2005 has been proposed to provide funds for treatment. Autism affects the legal system not only through legal actions for treatment access, but also because autistic individuals are more likely to have contact with law enforcement, either as crime victims or defendants, and to appear before the courts for family issues, including adult guardianship.

Don't get me wrong. On the day I received the news that my 2-1/2 year-old son was diagnosed with "autism in the severe range," I was devastated. Armed only with my lay understanding of the disorder, I walked away from that appointment with just two certainties: We were confronting a lifelong disorder for which there was no cure, and from the stern admonitions of the team of health care professionals who delivered the news, we needed to get moving, *fast*.

There is an urgency that parents of autistic children face. We quickly learned that our son's prognosis, to a large extent, rested squarely on our shoulders—on what we did or did not do right away—because intense, extensive therapy at the earliest possible age yields positive results for some children. Perhaps it was better that I knew so little at first and that the harsh realities of coping with a child with autism would only be revealed one day at a time.

Initially, I had absolutely no idea of what we were facing. I did not know that my son needed a minimum of 25 hours per week of intense treatment including, for example, speech, occupational, and behavioral therapy.¹ I did not know that there is a profound shortage of qualified therapists and therapy programs, and that such professionals can charge upwards of \$100 per hour or higher for their services. I was unaware that most health insurance programs will not cover such services. I did not know that public school districts, overwhelmed by the exponentially growing number of autis-

tic children in their charge, would fight to provide only minimal services, and that I, in turn, would have to arm myself with the law on special education to force the district to provide even a fraction of the services my son would require. Nor did I know that the emotional and financial burdens could strain a family to its limits, and that the estimated rate of divorce among parents of autistic children is 80%.²

The good news is that awareness of autism, and of the difficulties faced by families coping with this disorder, is improving. Parents, politicians, physicians, and lawyers are dedicating themselves to research, legislation, and other efforts to ease these burdens on families and to improve the availability and quality of treatment options for autistic children.

Prevalence

Statistics from the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) suggest that 1 of every 166 children have an autism spectrum disorder.³ Autism is the fastest-growing developmental disability in the United States, reflecting growth of about 10% to 17% each year. The disorder occurs in all racial, ethnic, and social groups, and impairs an individual's ability to communicate with and relate to others.⁴ National special education statistics showed a 657% increase in autism from 1993 to 2003.⁵

Critics of these figures, however, point to various confounding factors, such as lack of uniform diagnostic techniques and the possibility of diagnostic substitution, that is, a child who may have received a diagnosis of another developmental disorder 10 years ago may now be considered autistic. Indeed, the author of a study released this year from the University of Wisconsin-Madison indicated that the past decade's rise in autism prevalence did not reflect an epidemic and suggested, instead, that it was merely a diagnostic labeling issue.⁶ Nonetheless, the CDC estimates that of 4 million children born in the United States every year, about 24,000 will be diagnosed eventually with an autism spectrum disorder.⁷ That equates to 66 children diagnosed with autism every day or nearly 3 per hour.⁸

Diagnosis and Treatment

Private and public scientists alike are focused on research to identify better diagnostic and treatment options for autistic children. The NIH planned to spend \$99 million on autism research in 2005, compared with approximately \$22 million in 1997.⁹ However, advocates for autism research argue that these proposed research dollars are insufficient. According to some estimates, privately funded research on autism totals only \$15 million per year, whereas more than \$500 million is devoted to childhood cancers, juvenile diabetes, cystic fibrosis, and muscular dystrophy disorders that, even when combined, occur less commonly than autism.⁸

Current research efforts are nonetheless exciting and promising. Investigators from the National Institute of Child Health and Human Development have joined with the National Alliance for Autism Research to study the siblings of children with autism. By measuring verbal, visual, and social skills, the researchers hope to identify signs of autism before a child becomes a year old.⁹

Acknowledging that all autistic children are not the same, the Autism Phenome Project has been initiated this year to assess the different subtypes of children with the disorder, with the goal of targeting treatments that may be more effective for each uniquely autistic child.¹⁰ This large-scale longitudinal study, conducted by multidisciplinary physicians and scientists at the University of California, Davis, Medical Investigation of Neurodevelopment Disorders Institute, will examine the genetics, brain structures, blood proteins, immune systems, and environmental exposures of approximately 1800 children. The Project's researchers hope to build a strong database to examine the variability of autism to more effectively identify appropriate treatments.

In addition, the National Alliance for Autism Research recently launched a new collaborative effort, the Parents as Partners in Research program.¹¹ This initiative connects parents and families of autistic children with investigators who are conducting clinical studies aimed at early diagnosis, developing more effective treatments, and, we hope, finding a cure.

Genetics and Gender

Although some researchers believe there is strong evidence that autism has a genetic component, isolating the genes at issue has proved difficult. Studies have implicated the possible involvement of at least 15 or more genes. Parents of autistic children have established the Autism Genetic Resource Exchange (AGRE) to collect blood samples for clinical assessment and to share the data with qualified researchers who, in turn, must pledge to share any subsequent analysis. In 2003, the Autism Genome Project was launched with the goal of coordinating large gene banks, including AGRE, to aid in the study of the genetics of autism.¹²

Two recent studies in particular shed insight into the possible genetic implications of autism.¹³ A team of investigators from a number of institutions in Colorado examined magnetic resonance imaging (MRI) scans of the brains of parents of autistic children and compared them with control subjects. Some brain abnormalities found in the parents of autistic children were not found in the controls, including abnormalities in the cerebellum and basal ganglia, possibly indicating that the anomalies are inherited. In a second study, researchers from the University of Wisconsin–Madison used MRI and eye tracking to compare siblings of autistic children with control subjects. The authors found that non-autistic siblings displayed the same avoidance of eye contact that is often present in autistic individuals, again suggesting that the traits may be inherited.

Studies examining the genetics of autism may some day explain why boys with the disorder outnumber girls 4 to 1.⁹ Whereas an autism spectrum disorder is diagnosed in 1 of every 166 children, 1 of every 104 boys receives that diagnosis.¹⁴ Some researchers believe that the high prevalence of autism in boys may hold the key to understanding possible genetic causes. Simon Baron-Cohen, professor of developmental psychopathology at Cambridge University and director of its autism research center, has long theorized that autism is an example of the “extreme male brain.”¹⁵ This hypothesis holds that the essential difference between men and women is that women are

better at empathy, a trait with which autistic individuals struggle, and that men are better at systemizing, that is, deciphering how systems work in the world. The theory continues that autistic children, like men, study systems, and that some of their odd or repetitive behaviors, often viewed as obsessive, can be explained by the fact that the autistic child is intent to study, for instance, the means by which a fan blade turns.

In many respects, Baron-Cohen’s extreme male brain theory makes sense. After all, the most common characteristics of autism are difficulties with communication and with social relationships. As Baron-Cohen generalizes, girls tend to be more verbal whereas boys tend to be more spatial and physical, and men are more likely to be mathematicians or engineers, careers that require the comprehension and construction of systems.¹⁵ An extreme deficit of empathy could explain many autistic behaviors, because these children have great difficulty understanding that others have thoughts and feelings different from their own. An enhanced desire to systemize may explain why autistic children exhibit behaviors such as memorizing train schedules or staring endlessly at everyday objects.

The claim of an “extreme male brain” is more than just an amusing jab at the qualities of men taken to an extreme. This theory not only may be helpful in identifying a cause of autism, but also may help us acknowledge, accommodate, and appreciate the abilities and behaviors of children and adults with autism. In their drive to systemize, some autistic children may demonstrate remarkable skills. Some may collect and recall facts with amazing accuracy. Others will grow to excel at systemizing careers that can lead to great success. Many autistic individuals are simply and truly gifted. Understanding and nurturing these gifts, while at the same time addressing the deficits in other abilities of autistic children, is our greatest challenge.

Legal and Legislative Developments *The Cost of Autism*

Families with an autistic child can spend as much as \$100,000 per year on therapies.¹⁶

Insurance companies generally do not cover these expenses, and few families can afford to pay for them without assistance. Out of necessity, such families often turn with hope to their public school districts, which are charged under federal law with the obligation to provide a free appropriate education to all children. Public schools, however, find themselves ill equipped and underfunded to meet the needs of the growing number of autistic children in their care. In 2005, there were about 130,000 children with autism aged 6 through 17 years in public schools in this country, and the numbers have increased consistently in all states.⁹

The cost to accommodate an autistic student per year is approximately \$18,800, considerably higher even than an average special education student for whom the cost is about \$12,500 per year.⁹ As a result, highly charged legal and emotional battles have ensued between parents and school districts. At the heart of things, both parties share not only the same goal of providing effective treatment for each child, but also the same frustration and hopelessness in attempting to meet the mounting and overwhelming financial burdens.

Legislation

In response to persistent advocates, politicians are advancing legislation designed to ease the burden on some families dealing with autism. Upwards of 100 state representatives in South Carolina, for example, support legislation that would require insurers in that state to cover treatment options for autistic children.¹⁶ Insurers oppose the legislation, arguing that the higher costs, estimated at hundreds of millions of dollars, would be passed along to all consumers, could increase premiums by as much as 25%, and could affect families already struggling to keep up with rising health insurance premiums. Similarly, proposed legislation in Tennessee seeks to impose equity among the insured. Termed the Autism Equity Act and with a proposed effective date of July 1, 2006, the legislation would clarify that insurance policies presently providing coverage for neurological disorders should also cover treatment of autism

for persons under the age of 21, and would change the current classification of autism from a mental health disorder to a neurological/biological disorder.¹⁷ Attacking the problem from another angle, legislators in Virginia propose giving money to parents so they may send their disabled children to private schools.¹⁸ Public school advocates, however, have campaigned against the legislation, arguing that such vouchers would take badly needed resources away from public schools and could signal more school-choice bills in the future.

Other lawmakers have directed their energies toward research and more comprehensive programs. Last year, United States Senators Richard Santorum and Christopher Dodd introduced the Combating Autism Act of 2005. The Act would provide \$880 million for treatment, federal autism research, and public awareness programs over 5 years.¹⁹ Among other requirements, the Act directs the NIH to develop a budget for research on autism and to provide centers for excellence regarding research on autism. Pursuant to the legislation, the Secretary of Health and Human Services, acting through the director of the CDC, must establish regional centers of excellence in autism and a clearinghouse for the collection and storage of data. If the Act is passed, the Secretary must also award grants or cooperative agreements to develop statewide screening, diagnosis, and intervention programs and systems. The Act, which is currently referred to the US Senate Committee on Health, Education, Labor and Pensions, is the culmination of grass-roots initiatives by parents dedicated to the advancement of research on the causes of and treatments for autism.

The Courts

Any issue this emotional and frankly this financial is bound to make its way to the judicial system. Lawsuits brought by parents against their public school districts are becoming all too frequent, as parents struggle to enforce their child's right to a free and appropriate education pursuant to the 1975 Individuals with Disabilities Education Act. For example, in a 2005 case

in the state of Virginia, parents enrolled their autistic child in a private school out of concern that the class size in public school would preclude the one-on-one care the child required and because the school would not guarantee the services of a full-time aide.²⁰ A hearing officer found that the school district's plan for the child denied an appropriate educational benefit, and thus ordered the school district to pay for the cost of the child's placement at the private school. A series of appeals followed until, ultimately, the US Court of Appeals for the Fourth Circuit sided in favor of the child. In the process, however, the school district spent an estimated \$2,280,000 in attorney's fees and court costs on the legal matter, when the case could have been settled for approximately \$150,000, reflecting the parents' out-of-pocket expenses.²¹

Unfortunately, autism in the courtrooms is not limited to educational issues. It has been estimated that individuals with autism spectrum disorders have up to 7 times more contact with law enforcement during their lifetime than members of the general population.² Individuals with autism can be the victims of crime, including bullying, theft, and child molestation, because they are often vulnerable, unsophisticated, and easily manipulated. On the other hand, autistic individuals can be involved in the judicial system as criminal defendants, because their sometimes inappropriate, uncontrollable behavior can be confused with criminal intent or, again, because their vulnerability to manipulation can cause them to commit crimes they otherwise would not be inclined to commit. Moreover, as noted previously, a high divorce rate among parents of autistic children, often as a result of the emotional and financial strain that families face, brings autism into the courtroom, as custody is contested and a child's unique needs must be addressed. Lastly, probate courts are confronted more and more with the issue of autism, as families face difficult choices regarding guardianship, conservatorship, competency, and the ultimate protection of autistic individuals as they enter adulthood and are challenged by everyday life.

CONCLUSIONS

What do these recent legal and scientific developments mean for my son? Not much, I'm afraid. The critical years of early brain development are passing quickly now, and many of these well-intentioned efforts will not come to fruition in time to help him. For me, however, all the research, legislation, grassroots campaigns, and each of the struggles that are overcome, no matter how timely, have great significance. I am among the fortunate few who did not have to choose between therapy for my son and dinner on the table, and I am grateful for the tenacious progress he has made. My good fortune, however, does not blind me to the trials all families face when coping with a child with autism. Regardless of the severity of the disorder, the means of the family, and the unique struggles of each child, one cannot emerge from this process without becoming an advocate for families with autistic children and without hoping that future discussions of this issue may focus less on the struggles associated with autism and more on the gifts that each of these children brings to bear.

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Address correspondence to: Jane J. Bartley, Esq, Shook, Hardy & Bacon, LLP, 2555 Grand Boulevard, Kansas City, MO 64108. E-mail: jbartley@shb.com