

SCIENCE IN AUTISM TREATMENT

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THE NEWSLETTER OF THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Mainstream and Hope?

Lora Perry, MS
ASAT Board Member

My colleague Mark Steege, PhD, coined a phrase to describe the typical process of the education of children with autism in public schools: "mainstream and hope." This widespread practice is defended by some special educators on the logic that they are complying with the Least Restrictive Environment (LRE) requirement under the Individuals with Disabilities Education Act (IDEA). For many children with autism, however, mainstream and hope is a disaster.

First of all, let's look at what the framers of IDEA really intended: children with special needs should be educated in the least restrictive *effective* setting for that child. A setting in which the child is distracted by visually busy classrooms, overwhelmed by a bustling student body, or taught by an unquali-

fied and inexperienced individual is more isolating to the child than one set up specifically to meet his or her needs.

Secondly, IDEA promises a "free and appropriate education" (FAPE). As I see more and more school programs for children with autism, I find "appropriate" can mean, at best, "adequate," "good enough," "not too costly," and "not too troublesome." "Appropriate" frequently means a few hours a day with a teacher minimally qualified to teach children with autism. "Appropriate" can mean a child spending six or eight years of his life in a classroom with all the same children, and often the same teacher. "Appropriate" can mean not expecting too much—not trying to teach things that teachers "know" a child with autism cannot learn.

It can mean letting our children through the schoolhouse door, but not ensuring that they *learn* anything much once inside.

It is common practice in "mainstream and hope" – type programs for a child to be completely included in a regular education classroom with, at best, an "aide" (in some cases, a student's grandmother), and a regular ed teacher. Teachers charged with educating children with autism, and individuals who support those efforts, are likely to have no qualifications for teaching children with autism at all, let alone for doing so using vali-

dated methods. This falls far short of the educational integrity parents of typically developing children demand for their children. In other words, the diagnosis of autism may produce, in addition to all its other heartaches, a fundamental injustice: these special children can be denied effective education delivered by qualified individuals.

We *must* stop pairing our least qualified "teachers" with our most challenging students.

No matter how many times we sit with Pupil Education Teams and are told "it's not about money, it's about LRE," we know it's really about money. Professionals qualified to supervise and deliver an autistic child's education are scarce and expensive. Centers and community supports comprised of the proper resources with which to teach and treat children with autism have been springing up in many states, but they are costly. Somehow I think if we could figure out how to get the costs more comparable to those of a public education for typically developing children, there would be less conflict over



Joshua Perry, son of ASAT Board member Lora Perry and her husband, Steve.

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EDITORIAL*A Nation Recovers*

The Association for Science in Autism Treatment is based in Great Neck, New York, approximately 15 miles away from the tragic events of September 11, 2001. Several of our Board members and staff live in the tri-state areas surrounding New York City, and some had relatives working in the Financial District that day. Although we lost no one directly associated with ASAT, we, together with the rest of this nation, are profoundly shocked and saddened by the violence and loss of life. We extend our most sincere condolences and prayers to the victims and their families.

We have all been forever changed by the terrorist attacks on our country. However, President Bush urged Americans to "get on with the business of life," so that the terrorists do not disrupt our way of life. This issue of *Science in Autism Treatment* reflects ASAT's resolve to continue to provide accurate, science based information about autism, and to promote access to effective intervention.

In response to reader feedback, ASAT has determined that one way to improve our services is to bring a smaller issue of *Science in Autism Treatment* to you four times a year instead of twice a year. Beginning with this issue, our plan is to deliver a shorter newsletter each fall, winter, spring and summer.

Have you missed an issue? Check out all the newsletters on our website at www.asatonline.org. The website also has solid information about interventions for autism, ordering ASAT conference tapes, suggested readings, and much more.

We will continue to fight for the individuals we love who have autism. As editor of *Science in Autism Treatment*, I offer my prayer, God bless us all.

- Lora Perry, Editor

ASAT MISSION STATEMENT**THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT WILL:**

- Disseminate accurate, scientifically sound information about autism and treatments for autism; and
- Improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income, or place of residence.

WE WILL FULFILL OUR MISSION BY:

- Educating professionals and the public about state-of-the-art, valid treatments for people with autism;
- Supporting certification, to ensure all individuals with autism receive treatment from practitioners who have met minimum standards of competency;
- Forming interactive, supportive partnerships with universities to develop accredited educational programs for autism practitioners, and
- Improving standards of care for people with autism.

VALUES STATEMENT

ASAT is committed to science as the most objective, time-tested and reliable approach to discerning between safe, effective autism treatments, and those that are harmful or ineffective. ASAT supports all scientifically sound research on the prevention, treatment and cure of autism, as well as all treatments for autism that are shown to be effective through solid scientific research, regardless of discipline or domain.

utilizing these resources, and the passionate defense of "LRE" would diminish.

We need to change how we think about our educational investment in children with autism. The current perspective is nearly always based upon (inadequate) yearly special education budgets and "LRE." A smarter and higher cost/benefit perspective is one of long term investment. Imagine this: intensive, year-round, home-based effective intervention delivered by qualified individuals beginning immediately upon diagnosis. When the child has acquired specific predefined skills necessary to ensure success in more inclusive settings, begin to expand the child's world to those settings using supported inclusion (which is a detailed process, not mainstream and hope.) As the child acquires more predefined skills, fade the supports. Such a well planned and disciplined long term vision of how to educate children with autism just might emancipate enough children from special services to liberate money to fund this longitudinal model.

Not all children with autism will acquire the skills necessary to successfully mainstream. The team overseeing the child's education should continuously evaluate the rate of the child's learning. If this is determined to be slow, take a hard look at all of the components of the program. Is the staff sufficiently qualified? Do they get adequate direct contact supervision by a qualified professional? Are we teaching to the child's mode of learning? Is the program sufficiently intensive? If the

The diagnosis of autism may produce, in addition to all its other heartaches, a fundamental injustice: these special children can be denied effective education delivered by qualified individuals.

answers to these questions are legitimately (and not conveniently) yes, the plan can be altered at any time. But if we set the bar high at the outset, we allow the *children*, not some predetermined political or budgetary condition, to show us how far and how quickly they can progress.

This is in contrast to typical public school programs offered for children with autism, which are frequently necessary throughout the students' entire school career; when the students "graduate" from public school at age 21, they enter the publicly-funded adult system of care for the rest of their lives.

As adults, individuals with disabilities have the legal right to live in the most integrated setting possible. As more and more very fortunate children with autism gain access to the **effective** services they need, we are seeing longterm outcomes improve, including recovery from autism. It is only a matter of time before some desperate parents band together and sue someone, *anyone*, for condemning a child with autism to the likelihood of lifelong dependency due to the absence of effective childhood services. This void goes by different terms in different circles, but among them are malpractice, neglect and abuse.

Mainstream and hope is a bad investment. *It breeds dependency.* Fortunately, I have been blessed with a particularly insightful special education director. As a consequence of her investment in good, intensive, effective intervention for the last three years, my son Jason is becoming independent and able to learn from mainstream settings. It is our hope to have Jason fully and

meaningfully mainstreamed in a year or so. Based upon what we've seen around us, this would be unlikely had he been in a "less restrictive" setting these past few years. I fully expect Jason to defy the odds of being dependent upon others for the rest of his life.

As parents and advocates, we need to ensure that mainstream and hope becomes a relic of the past, an outmoded ideology that we saw fit to replace with a system guaranteed to maximize each child's potential for the fullest possible development, integration, and independence.

SIDEBAR:

What's the Alternative to Mainstream and Hope?

1. Pupil Education Teams must agree upon objective, measurable criteria by which to determine when a child can benefit from mainstream settings. My Pupil Education Team and the special purpose school for children with autism where I work use the supported inclusion criteria outlined in *Behavioral Intervention for Young Children with Autism*.
2. Plan the multi-year path. Equip the child with the skills necessary to succeed in mainstream settings based upon objective criteria.
3. Prepare the school environment with the environmental and human resources supports the child needs. Be sure to insist upon properly trained and supervised staff. Ask for copies of resumes and CVs to verify qualifications, and check references.
4. Re-commit to the value that when the framers of IDEA invented the Pupil Education Team, they truly meant it to be a Team *process*, very much involving and honoring the judgement of parents. Parents should attempt to work cooperatively with all levels of school administration, but when their voices are ignored and their children's interests are betrayed, they should not hesitate to apply for redress through any means, including legal, at their disposal.



Madison, daughter of ASAT supporters Christie and Jeff Plaisance.

BOOK REVIEW

The Power of Positive Parenting

Dr. Glenn I Latham, P&T Ink, 2000 (435-752-0238)

Shirley Tawney, MS
Guest Contributor

"Misbehavior of children must be recognized as a need to teach appropriate behavior, not an excuse to punish. Punishment is a terrible teacher. It only teaches children how not to behave." (p.7)

"A disciplined child is a product of a disciplined environment." (p.27)

"I want to read everything Dr. Latham has ever written."

"I tried this with my granddaughter and it really does work!"

"My teenagers were really going at each other. I told the kids to sit down and read Dr. Latham's chapter on "Sibling Rivalry." They said, "Hey this is cool, Mom. May I read more?"

These are some of the comments adult students made recently in the Applied Behavior Analysis class I teach. *The Power of Positive Parenting* is required as one of the texts, because I have found it to be a powerful way to teach the basic principles of human behavior simply and pragmatically.

In the preface, Dr. Latham writes "So far as the author has been able to determine, the book has been subjected to more independent, scientific scrutiny than any parenting book in print today." He then challenges readers to verify his assertion: "Summaries of studies conducted on the book, the documented impact the book has had on families, and unsolicited testimonials from parents are available from the author." In an age when parenting books based upon varying "philosophies" abound, it is refreshing to have at least one that makes an attempt at science-based effectiveness.

Dr. Latham presents his material with a dry and engaging wit: "As parents, we must realize that children are

in the process of becoming civilized" (p. 39). He is, at times, heretical: "It is not necessary for the parent to always be right" (p. 132.)

Dr. Latham counsels patience and discipline: "Parents are often looking for a quick fix, something that will turn a monster into a dream child overnight. That's not what I'm talking about in this book. I'm talking about a gradual, methodological, systematic approach to organizing an environment that will reinforce children for behaving well" (p. 38).

"Junk behaviors" are described as "age-typical, garden variety, weed behaviors that go along with growing up," behaviors that should be ignored while desirable behaviors are reinforced.

Some children with autism may have more of their share of "junk behaviors," and *The Power of Positive Parenting* is not written specifically to address parenting children with autism. Nevertheless, the book is a credible response to the question so many parents of newly or long ago diagnosed children of autism pose: Where do I turn for information now? How do I parent my child?

When read by parents, teachers, grandparents and others, *The Power of Positive Parenting* is a guide for using sound, scientific behavioral principles and techniques to solve common problems we face with children today. Here are a few headings: On Being In Control, A Word About Consequences, Dealing with Hate and Anger, Eliminating Tantrums, Eliminating Tattling, Eliminating Lying and Stealing, Eliminating Thumb Sucking, Refusing to Do As Told, Living with Teenagers: A Better Way, and Helping Children Achieve in School. These, and 17 other chapters, help breathe order into child rearing chaos.

Most helpful of all are model situations that can go one way or another:

handle it inexpertly, and undesirable behavior is reinforced. Handle it as Dr. Latham suggests, and reports are a teachable moment has been seized.

Over my 43 years as a public educator, parents and teachers frequently asked me questions about how to improve children's behavior, and how to help better prepare children for their responsibilities ahead. I wish I had had this book to give to each one of them, so parents and teachers could have access to the scientific behavioral techniques that really do work. Every parent, grandparent, aunt, uncle, teacher and administrator should read *The Power of Positive Parenting*.

In Memoriam Glenn I. Latham, Ed.D.

Catherine Maurice
President
ASAT Board of Directors

It is with sorrow that the Board of Directors of ASAT notes the passing of Dr. Glenn Latham, who died suddenly on July 10, 2001. Author of numerous books and papers on effective teaching strategies in both home and school settings, and an acclaimed scholar and lecturer, Dr. Latham was known to thousands of parents, educators, behavior analysts and psychologists

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Does the MMR Vaccine Cause Autism?

The following is edited for length and re-printed from the Centers for Disease Control's (CDC's) website at <http://www.cdc.gov/nip/vacsafe/concerns/autism/autism-mmr.htm>, with permission.

Current scientific evidence does not support the hypothesis that MMR vaccine, or any combination of vaccines, causes the development of autism, including regressive forms of autism. Epidemiologic studies have shown no relationship between MMR vaccination in children and development of autism. Taylor et al. (1999) studied 498 children with autism in the UK and found that the age at which they were diagnosed was the same regardless of whether they received the MMR vaccine before or after 18 months of age or whether they were never vaccinated. Importantly, no clustering of developmental regression was found after vaccination. Also, there was no "step up" in cases of autism or change in the trend line after introduction of MMR vaccine. Gillberg and Heijbel (1998) compared the prevalence of autism in children born in Sweden from 1975-1984. There was no difference in the prevalence of autism among children born before the introduction and after the introduction of the MMR vaccine. A recent study (Kaye et al., 2001) assessed the relationship between the risk of autism among children in the UK and MMR vaccine. Among a subgroup of boys aged 2-5 years, the risk of autism increased almost 4 fold from 1988 to 1993, while MMR vaccination coverage remained constant at approximately 95% over these same years. Similarly, among children born in 1980 to 1994 and enrolled in California kindergartens, there was a 373% relative increase

in autism cases, though the relative increase in MMR vaccine coverage by the age of 24 months was only 14% (Dales et al., 2001). These data do not support a causal relationship between MMR vaccination and risk of autism.

In 1999, the British Committee on Safety of Medicines convened a "Working Party on MMR Vaccine" to conduct a systematic review of reports of autism, gastrointestinal disease, and similar disorders after receipt of MMR or measles/rubella vaccine. It was concluded that the available information did not support the posited associations between MMR and autism and other disorders. In addition, in 1997, the National Childhood Encephalopathy Study (NCES) was examined to see if there was any link between measles vaccine and neurological events. The researchers found no indication that measles vaccine contributes to the development of long-term neurological damage, including educational and behavioral deficits (Miller et al., 1997).

What about other studies that suggest there might be a connection between autism and MMR vaccine?

Current scientific evidence does not support the hypothesis put forth by Wakefield and colleagues (1998) that the MMR vaccine causes the development of autism, including regressive forms of autism.

Wakefield et al. (1998) reviewed reports of 12 children with bowel disease and regressive developmental disorders, mostly autism. In 9 of the cases, the child's parents or pediatrician speculated that the MMR vaccine had contributed to the behavioral problems of the children in the study. This was the only evidence suggesting a possible link with vaccination.

This study was reviewed by an expert committee from the UK Medical Research Council (MRC). The Council concluded **there is no evidence to link the MMR vaccine with autism.** On April 3, 2000 the MRC issued a new report confirming its earlier conclusion; MMR has not been linked with inflammatory bowel disease or autism. A copy of this report can be found at the MRC web site, <http://www.mrc.ac.uk>.

What about the claim that the numbers of children with autism have been increasing ever since the MMR vaccine has been in use?

The data from California (Department of Developmental Services, 1999) used to illustrate an increase in cases of autism were presented inaccurately (Fombonne, 2001). Fombonne (2001) lists several reasons why the data are misrepresented, for instance: 1) the figures presented are based on numbers, not rates, and do not account for population growth and changes in the composition of the population, 2) changes in diagnostic definitions were not controlled in the report, and 3) as in other areas of the country, children with autism are currently being diagnosed at earlier ages meaning that there will be an increase in the number of reported cases.

Should a younger sibling of an autistic child, or a child of someone who has autism be vaccinated with MMR or other vaccines?

Yes. Current scientific evidence does not show that MMR vaccine, or any combination of vaccines, causes the de-

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HELP DESK

Bobby Newman, PhD, BCBA

Dear ASAT: My child isn't sleeping through the night. She tantrums in her room when we put her to bed, or winds up in our bed. What can we do?

I'm afraid I don't have a specific answer to your question. I wish I could give you a book that says "for all perseverative behavior, do this" and "for all self injurious behavior, do this." There's no such book, and anyone who tells you differently is selling something. There is no substitute for a good functional analysis of the behavior in question. Still, we can start with gathering information you need to proceed.

Does your child ever sleep through the night? Under what circumstances? Is your child happy in her bed if you are in the room? Are bathroom and other bodily needs (hunger, thirst) satisfied by bedtime? Does your child go to bed and then come out, or does she not even go in at all? Does your child sleep during the day? How many hours does she generally sleep a night? Is it possible there is too much sleeping during the day, or that might you be putting her to bed too early?

If your child is sleeping a lot during the day, she may not be sleepy at night. Cut out the afternoon naps, and the problem may be solved. Consult your doctor regarding how much sleep your daughter should need at her age. Classical conditioning may also play a role. It is never a good idea to have someone go to bed who is not going to fall asleep any time soon. The bed should be a conditioned stimulus for sleep. If there is no hope of the child being sleepy, being in bed is not conducive to the bed becoming a signal for sleep. You may have a "house rule" that says to stay in your room after a particular hour, but you can't make someone sleep.

If it isn't something so obvious, we

have to begin our "detective work." Does the child ever sleep through the night? If so, when? Can it be that your house is too stimulating at night? Are televisions or radios going? Are there loud conversations and a lot of laughing? Is it possible the child is missing potent reinforcers when she goes to bed? If so, access to those reinforcers needs to be curtailed until the "habit" is broken.

Often, children have difficulty with the lying down in the first place. Is the child anxious? If so, you might need to stay with the child and then fade yourself away from the setting. This can be done by sitting with the child until she falls asleep at first, and then systematically fading your presence. You might sit further and further from the bed and then eventually not be in the room at all, or progressively stay for less and less time each night. The key is to fade yourself gradually.

In extreme cases, the ritual must simply be broken by having the child stay in his/her room and redirected back if they leave. The child may tantrum within the room, so think ahead and "child proof." Be careful with this. Don't undertake this type of plan unless you are prepared to carry it through all the way, or you will intermittently reinforce the behavior. Inconsistency on our part breeds persistence in our children.

In all cases, remember the basic rule of reinforcing what you want to see. Don't expect that behavior will occur just because you said so. When you see good examples of the behavior, reinforce heavily.

I recommend V. Mark Durand's book titled *Sleep Better!: A Guide to Improving Sleep for Children with Special Needs* for more on systematic ways to help your child improve her sleep habits. (Available from Amazon.com.)

Bobby Newman, PhD, is author of the book *When Everybody Cares: Case Studies of ABA With People With Autism*.

IN MEMORIAM

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worldwide.

I came to know him when I stumbled across two of his books: *The Power of Positive Parenting* (an exposition of positive strategies to help parents raise and teach their children well); and *Behind The Schoolhouse Door* (an overview of key principles and techniques for effective classroom management and teaching.) My discovery of these works was somewhat bittersweet. I remembered my year as a graduate student in a Master of Arts in Teaching program, an experience whose applicability to actual classroom teaching could fit into a teaspoon, and wondered, "Where was *Behind the Schoolhouse Door* when I needed it? Why is this work not mandated in every single school of education, in every single university, across the country?" Its precepts are clear, straightforward, logical. Its examples ring true to life. Its explanations and rationales are smart, no-nonsense, and loving. In one afternoon of reading this book, I could have drawn more practical advice and confidence as a teacher than I did in all those hours and hours of theoretical discussions on the philosophies of Jean Jacques Rousseau, John Dewey, Piaget, etc; than all those droning demonstrations of How to Use an Overhead Projector, How to Write a Lesson Plan; and on and on.

As to *The Power of Positive Parenting*, again, the experience of reading this book was almost too strong: Here was a near-perfect translation of behavior analytic principles and techniques into a clear and cogent guide for parents like me, for parents everywhere, who daily struggle with the delicate and complex decisions that go into child-rearing. Dr. Latham was able to demonstrate, over and over again in his books and lectures on parenting, that loving parents are not

afraid to set expectations, limits, and consequences. He was able to speak out strongly against physical and emotional abuse of children, while at the same time outlining positive, firm and consistent modes of teaching, guiding and leading those young lives entrusted to our care. Bombarded by a culture that seemed to vacillate between nonsensical extremes of permissiveness and punitive abuse of children, again I longed to be able to place this book into the hands of every parent I knew, every parent who struggled, every parent who was overwhelmed by too many conflicting theories. Look, I wanted to say, just read this book and see if its precepts do not ring true, see if it is not grounded - in research, logic, common sense, and love.

The last time Dr. Latham and I spoke, over dinner, the conversation turned to that cultural confusion about what discipline is, what good teaching consists of, what behavior analysis is, and how hard it is to keep speaking out on these topics. Glenn spoke with sadness of some of the painful mistakes he has witnessed in both home and school settings. "How do you go on?" I asked him. "Don't you get tired? I have been trying to do some writing and advocacy myself for ten years, and I am so disheartened by the 'autism wars,' the confusion about discipline, the prejudice against applied behavior analysis, the suffering of children who are denied effective education."

"Ten years?" he responded with a smile. "Ten years? My dear, I have been doing this for over forty years, and I hope to continue for many more."

Sadly, Dr. Latham was not to be granted that hope. But the legacy of wisdom and compassion and experience that he left behind remains a gift for all of us, and it is monumental.

Help ASAT Continue Our Important Work!

The Association for Science in Autism Treatment was founded to provide accurate, science-based information about autism, and to promote access to effective treatment. Too much time has already been wasted for too many children, and far too many families have exhausted their emotional and financial resources in an effort to access **effective and scientifically validated** information and treatment for their children. Parents, advocates, therapists, educators, service providers, attorneys and hearing officers need accurate information in order to make well-informed decisions on behalf of our children—decisions that have the potential to enhance or compromise their quality of life.

ASAT's newsletter, website, information packets and conferences put this vital information directly into the

hands of those charged with the care of our children, and those making decisions in their lives. But we can't do it without your ongoing financial help. Please make a pledge for a one-time or monthly contribution charged to your VISA or Master Card, or send a check to the address listed below. Your donations support the publication of our newsletter *Science in Autism Treatment* distributed free of charge; information packets for parents and professionals; and conferences around the country that bring concrete information about state-of-the-art, effective treatment for our children.

Please help, by giving as generously as you can. Contributions should be sent to the ASAT office at 175 Great Neck Road, Suite 406, Great Neck, NY 11021.

Thank you!

Rave Reviews for ASAT's Conferences

ASAT's 2nd Annual Conference, *Science in Autism Treatment*, was held in San Diego on March 8-10, 2001. The conference, designed to disseminate scientifically sound information about autism and its treatment, featured world-renowned researchers, clinicians and practitioners from the biomedical and behavioral arenas. Over 400 parents and professionals were presented with state-of-the-art information on the topics of Pharmacology, Genetic Research, Behavioral Intervention, Neural Plasticity, Immunogenetic Research and Speech/Language Research and Practice.

Portland, Maine was the setting for ASAT's first one-day Regional

Conference, *ABA: Maximizing the Potential of Children, Parents and Teachers*. The conference, held on September 21st, provided critical information to parents and professionals about the design and implementation of **effective** teaching strategies for children and adults with autism.

Attendees consistently report that ASAT conferences bring valuable information to parents and professionals alike. This type of outreach to the autism community is at the heart of ASAT's mission. If you wish to have ASAT present a conference near you, contact Marissa Bennett at 516-466-4400 or email ASAT@autism-treatment.org.

Does the MMR Vaccine Cause Autism?

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velopment of autism, including regressive forms of autism.

A younger sibling or the child of someone who suffered a vaccine side effect usually can, and should, safely receive the same vaccine. This is especially true since the large majority of side effects after vaccination are local reactions and fever, which do not represent a contraindication.

Should we delay vaccination until we know more about the negative effects of vaccines?

No. There is no convincing evidence that vaccines such as MMR cause long term health effects. On the other hand, we do know that people will become ill and some will die from the diseases this vaccine prevents. Discontinuing a vaccine program based on unproven theories would not be in anyone's best interest. Isolated reports about these vaccines causing long term health problems may sound alarming at first. However, careful review of the science reveals that these reports are isolated and not confirmed by scientifically sound research. Detailed medical reviews of health effects reported after receipt of vaccines have often proven to be unrelated to vaccines, but rather have been related to other health factors. Because these vaccines are recommended widely to protect the health of the public, research on any serious hypotheses about their safety are important to pursue. Several studies are un-

derway to investigate still unproven theories about vaccinations and severe side effects (www.cdc.gov/nip/vacsafe/concerns/autism/autism-res-cdc.htm; www.cdc.gov/nip/vacsafe/vsd/research.htm).

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