

# AMA Journal of Ethics

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# AMA Journal of Ethics

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## FROM AN AMA JOURNAL OF ETHICS SPECIAL CONTRIBUTOR

### Making Ethical Progress without Ethical Theories

Dien Ho, PhD

#### The Couple

A young couple plans to start a family. A month into her pregnancy, the mother-to-be realizes that balancing work, education, and starting a family will be more than she is ready to handle. She talks to her partner, and he expresses his desire for her to carry the child to term and reminds her that she did commit to the pregnancy. Should she be allowed to terminate the pregnancy against her partner's wishes [1]?

#### The Problem

The typical way ethicists tackle an applied question like the one above is by deploying a favored ethical theory and finding out what answer falls out after plugging in the "values for the variables." Most health care ethics textbooks and courses subscribe to this approach and design the pedagogy by first introducing a plethora of ethical theories before tackling applied ethical issues such as patient confidentiality, euthanasia, abortion, and so on. This approach relies on an implicit belief that learning ethical theories is a necessary if not sufficient part of solving everyday ethical problems. The popular text book (that I use in my courses) *Ethical Issues in Modern Medicine* by Bonnie Steinbock, Alex London, and John Arras, for instance, outlines fifteen ethical and meta-ethical theories in its introduction [2]. These theories range from moral nihilism, to rule-utilitarianism, to feminist ethics, to casuistry. But this crash course on ethics and meta-ethics does not tell us which of the competing ethical and meta-ethical theories we should use to figure out what one ought to do. The gap between theories and application exists because ethical theories often make competing recommendations and we do not know which theory we ought to use. In the example above, a utilitarian might conclude that, in the long term, terminating the pregnancy would maximize utility for the most people, and therefore the mother-to-be ought to do it. A deontologist, on the other hand, might disagree and conclude that the mother-to-be has a duty to keep her promise. It seems that unless we first settle on the "right" moral framework, we can never solve any ethical problems.

Steinbock et al. clearly recognize the pedagogical and conceptual gulf between theories and practice, and they suggest that having so many ethical theories contributes to

an extraordinarily complex moral reality. Still, in deciding what to do, one must decide when utilitarian considerations should prevail, or when one

ought to adhere to absolutist principles; when to appeal to principles and when to seek guidance in virtues; when to abide by universal, impartial considerations and when to concentrate on personal relationships and feelings [3].

Steinbock et al. echo what many philosophers have suggested: we need to consider all the ethical frameworks and attempt to achieve coherence among our moral beliefs.

Simply maintaining coherence is not difficult, but it does not resolve moral questions. When presented with merely two conflicting moral beliefs, coherence demands only that we reject at least one; it does not dictate which moral belief we ought to reject so long as we reject at least one. Imagine the many possible coherent outcomes when an ethical problem presents multiple mutually incompatible propositions. Coherence will not suffice in helping us determine what we ought to do.

Moreover, the demand for coherence is itself a moral value system, in which consistency is prioritized above other possible concepts of the right or good. It might prove psychologically comforting to strive for greater coherence in one's reasons and actions, but a recommendation based on coherentism is not necessarily right without a prior assumption that coherentism is the correct moral theory.

### **Ethical Theories Are Secondary in Resolving Everyday Moral Disputes**

The idea that we need ethical theories to tell us what we ought to do might strike most laypersons as awkward and artificial; e.g., consider how odd it sounds to decide whether one ought to continue a pregnancy by seeing if it maximizes utility [4]. The fact is we frequently resolve ethical disputes in our daily lives, often paying little attention to ethical theories. To be sure, when challenged, many of us justify our moral choices on the basis of some ethical theories, but the appeal to theories is often a form of post hoc rationalization. Psychological studies done by Jonathan Haidt support this view [5]. Of course, the fact that we use moral theories to rationalize our choices post hoc does not entail that moral theories are merely window dressing. However, if one goal of the study of ethics is to provide a relatively accurate description of our moral reality (e.g., how we reason morally), then surely it should account for the glaring absence of appeal to ethical theories in everyday moral reasoning. To suggest—as introductory ethics courses do—that moral reasoning must flow down from broad theories to specific moral recommendations is to fly in the face of how we actually decide what we ought to do. It makes one wonder whether such a model in fact concerns *our* ethics [6].

A comparison with empirical sciences can perhaps illuminate the relationship between deep ethical theories and ordinary moral discourse. In science, researchers rarely engage questions of why certain fundamental laws are true. Instead, they deploy heuristics and “midlevel” theories or generalizations to tackle their problems. For instance, a biologist

might rely on the rules of Watson-Crick base pairing that the purine adenine always pairs with the pyrimidine thymine and the pyrimidine cytosine always pairs with the purine guanine. The regularity of the pairing can be explained by understanding hydrogen bonding, but this deeper explanatory step is rarely, if ever, needed in conducting everyday research in genetics. Typical moral decision making relies on heuristics much like the rules of Watson-Crick pairing: these heuristics allow us to identify which moral beliefs we should hold but they float above the explanatory project (ethical theorizing) of trying to figure out *why* these beliefs are true.

So far I have only sketched a negative thesis; that is, when we make moral decisions in our daily lives, we rarely appeal to broad ethical theories. Nevertheless, when we attempt to convince ourselves and others that a particular moral decision is appropriate, we need to find some way to justify it. Appealing to a specific ethical theory for justification only means that we then need to provide further justifications for choosing that particular ethical theory. What is required to justify our moral choices must lie beyond specific ethical theories. In order to identify the appropriate justificatory source, let us reexamine why we need ethics in the first place.

### **Why Ethics and the Default Principle?**

We often appeal to ethics to adjudicate disagreements such as those between two parties whose interests cannot both be satisfied, for instance, an asymmetric moral disagreement in which A wants to do X and B wants her not to [7]. Of course, we can adjudicate disagreements in a number of ways—we could resort to violence, drawing straws, bribery, guilting or shaming one party or another, and so on—but when we choose to resolve disagreements by appealing to ethical considerations, we agree to allow reasons to be the ultimate arbiter of what we are permitted to do. This broad characterization of ethics as rational conflict resolution generates some interesting results. For starters, it tells us that one party can only impose its will on another by appealing to reasons. Moreover, in the absence of a compelling reason not to, individuals are permitted to do what they wish [8]. Call this the default principle (DP).

DP follows a recognition that we offer reasons to ethically justify our actions only when these actions affect another person. In an asymmetric disagreement, there are logically two possible ways the use of reasons might resolve the conflict: either A offers a reason for why she is permitted to X or B offers a reason for why his prohibition of A doing X is warranted. Of course, to say that A must offer a reason for why she is permitted to X is to say that unless a reason is offered, she cannot X. But surely this is absurd. Imagine if A is all by herself on a desert island. She does not need to offer a reason to morally justify her actions before she does them. Her actions only require justifications when they run into the interests of another party. Thus, in an asymmetric disagreement, B has to offer a reason for why his prohibition of A doing X is warranted; which is to say, unless there are reasons to think otherwise, A gets to do what she wants (i.e., the DP). The insight that

ethics arise only when interests collide is behind much of the Enlightenment philosophers' appeal to the state of nature [9].

The DP has what might be called a "permissive bias": the burden of proof always rests on the side that wishes to restrict another's autonomy. Thus, regardless of whether A can articulate why she should be permitted to do what she wants, as long as B fails to supply a good reason why she should not, A is permitted to do what she wants. Moreover, suppose for a moment that a genuine impasse exists between the two parties; e.g., the disagreement rests on a difference of values—something that is typically based on subjective preferences. By definition, no reason exists to limit A's autonomy; hence, A must be permitted to do as she pleases. Both of these results—B fails to supply a reason for A's not doing as she wishes, so she does as she wishes, and A and B differ in their values, so rational argument is a hopeless task, and A gets to do as she wishes—reflect a permissive bias. Indeed, they echo a typical liberal slant that conservative ethicists have complained about. If the permissive bias is in fact a product of liberal values, then their criticism is correct. One would need to provide an argument to support the allegation that the permissive bias derives from liberal values, and, given the fact that they are values, arguing to establish their exclusive source in liberal thinking appears to be an impossible task.

Our permissive bias stems not from the acceptance of liberal values or, for that matter, any specific ethical framework. It comes from the very ground rules of appealing to reasons to resolve conflicts; that is, the need to provide a reason to morally justify one's actions only arises when it compromises the interests of another party. In this respect, the permissive bias transcends ethical frameworks, and it helps us avoid the earlier problem of how we go about justifying a moral decision without locating the "right" ethical theories, at least in the cases of absence of arguments.

The scenario outlined at the start of this essay provides an example of how the default principle can guide us through an ethical conundrum. Given the default principle, the side that wishes to override the woman's desire to terminate her pregnancy must supply reasons to justify that position. If, after they are evaluated, the reasons offered remain inconclusive, she must be permitted to terminate. Her failure to offer any reasons to defend her preferences does not undermine her right to proceed. In this sense, the default principle provides a permissive bias without assuming liberal values. Of course, we still need some way to evaluate reasons offered that does not presuppose a specific ethical framework. In the next section, I will derive a justification for appealing to arguments by parity from the default principle.

### **Generating Arguments by Parity from the Default Principle**

The default principle justifies a certain kind of moral coherentism by way of its use of arguments by parity. In determining what moral attitude we should take towards a

particular practice, it is common for us to identify the moral belief we have towards similar practices. For instance, the argument in favor of legalization of same-sex marriages centers primarily on the idea that same-sex and heterosexual marriages are very similar and therefore equally acceptable. The proponents of legalizing same-sex marriages have argued that there are fundamentally no reason-based differences between the two types of marriages that are relevant to making decisions about whether it is ethical. That is, the standard reason given for allowing marriage only between members of different sexes is that the purpose of marriage is procreation, but infertile couples are allowed to get married; thus, same-sex couples' inability to procreate without external assistance cannot justify prohibiting same-sex marriages. The force of this argument is that logical consistency demands that either we reject a deeply entrenched belief or change our minds and assign the same moral attitude towards the practice in question.

An argument by parity does not need to rely on some broad ethical framework. A commitment to logical consistency is all that is necessary to appreciate the argumentative force, and this commitment comes not from a blind worship of logical consistency but from the default principle. Suppose there are no practical differences between X and Y that would cause us to judge them in ethically different ways. To prohibit X but not Y would be to prohibit X without a reason (since if there were a reason, it would suffice to prohibit Y as well). A rejection of a sound argument by parity is thus a rejection of the default principle.

### **Default Principle Limitations**

The default principle has some limitations.

*The requirement of some shared beliefs.* Arguments by parity require there to be some shared moral beliefs to provide sufficient purchase to make the analogy work. If two individuals share no moral beliefs, arguments by parity would be useless. Exactly how far we can go with only a few shared beliefs is an important question that demands empirical answers. My suspicion is that we can make a great deal of progress with a handful of shared basic moral beliefs (e.g., all else being equal, one ought not choose a course of action that causes more suffering).

*The possibility of expanding, rather than closing, gaps in belief.* Another serious problem with arguments by parity is that in the face of logically incompatible moral beliefs one always has at least two choices: accept the new moral belief and abandon the firm belief that one once held, or retain the firm, long-held belief and reject the new belief. In other words, logical consistency merely insists that one cannot stay at a particular doxastic spot; it does not tell one whether to move closer to or further from the beliefs of the other disputant. If the anchoring belief is firm enough, the cost of revising one's web of beliefs would be so high that the agent would abandon the new belief as the path of

lesser resistance. But of course psychological ease is no guide of morality or rationality [10].

The inability to compel one's opponent to move morally closer (as opposed to further) is an obvious possible outcome of utilizing arguments by parity. Nevertheless, I suspect that this feature is less a dialectical defect than a variance of Hume's problem of justifying rationality, to wit, there is no absolutely secured foundation upon which to attempt to justify rationality without using reason—the function we are attempting to justify. All reasoning must involve constant adjustments among competing beliefs in a sort of reflective equilibrium [11].

*The permissive bias does not apply when autonomy is not restricted.* There will be disputes in which no one side is clearly restricting the autonomy of another. For instance, if two individuals argue over which of them should receive a liver transplant, their statuses vis-à-vis the default principle would be symmetric. This is a symmetric disagreement. In this respect, the permissive bias is irrelevant, and we must evaluate the relative merits of both of their positions. This shortcoming is not unexpected given the fact that the permissive bias and subsequent default principle come from accepting the ground rule that the imposition of will can only be permitted when there is reason to justify it. When no party is attempting to impose his or her will on another, the asymmetry necessary to generate the permissive bias is absent.

### **Implications of the Default Principle**

The diversity of ethical frameworks that participants in a moral dispute hold tells us that, if solving a moral dispute or question means deriving a proper course of action on the basis of the "right" moral framework, no moral problem can be solved. Yet we are often capable of solving moral problems. A great deal more research is needed to get a better understanding of how we make moral judgments, but a few things should be apparent. Firstly, an understanding of the nature of ethics as consisting of appealing to reasons to solve conflicts generates some important justificatory and methodological consequences that have been for the most part unnoticed. Agreeing to settle disputes by recourse to reason provides us with a rough roadmap of how to proceed without presupposing a particular moral framework. This allows us to avoid the justification problem that plagues those who subscribe to the orthodox "trickle-down" view.

The efficacy of the default principle to resolve ethical disputes without necessitating recourse to a particular moral framework suggests that we should reevaluate the way clinical ethics is taught and conducted. The standard pedagogical approach of introducing a plethora of ethical theories as the beginning of training in ethics is unnecessary and most likely unhelpful in providing clinicians with the tools to tackle real-life ethical problems. Teaching students how to identify asymmetric arguments, understand their structures, and use practical reasoning skills, and familiarizing them with mid-level moral



principles, are far more useful. Likewise, the hesitation (e.g., the view of the American Society of Bioethics and Humanities) about ethics consultation services that make clear recommendations is unwarranted if the hesitation stems from worries that various ethics consultants might impose their own ethical assumptions and values on those who do not share them. The default principle tells us that, as long as we agree to resolve our moral conflicts by appealing to reason, there are methodological principles that transcend particular ethical frameworks.

## References

1. This is the core conflict in *Planned Parenthood of Central Missouri v Danforth* 428 US 52 (1976).
2. Steinbock B, London AJ, Arras JD. *Ethical Issues in Modern Medicine: Contemporary Readings in Bioethics*. 8th ed. New York, NY: McGraw-Hill; 2013.
3. Steinbock, London, Arras, 35.
4. We often use midlevel moral generalizations (e.g., do what maximizes the benefits of most people) to help us reason morally. These midlevel moral generalizations are not ethical theories in the traditional sense of providing a foundation for morality. Rather, they are rough rules of thumb that we do not hesitate to abandon when we intuit that using them in a particular situation is inappropriate. In other words, these midlevel rules do not serve the deep explanatory or justificatory role of any grand moral views.
5. Haidt J. The emotional dog and its rational tail: a social intuitionist approach to moral judgment. *Psychol Rev*. 2001;108(4):814-834.
6. For any philosophical investigation, we often have to strike a fine balance between the descriptive component (the way X is) and the prescriptive component (the way X ought to be). If a study merely provides a descriptive component, we would not be doing philosophy but, say, sociology. Likewise, if it is purely prescriptive, then one wonders what the project has to do with the initial subject matter. Ethics is unique in that all of us are intimately familiar with it. We are, to borrow a phrase from linguistics, "competent speakers" of the language of ethics. An analysis that tells us we are radically wrong in how we reason morally would be akin to a linguist who studies a native French speaker and concludes that she actually doesn't speak French.
7. It is an asymmetric disagreement because the object of B's want is A's refraining from X. If A wants X and B wants Y and X and Y cannot be jointly satisfied, then we have a symmetric disagreement.
8. We must accept this statement for now without listing explicit criteria for what makes an argument "compelling" in order to further develop the thesis that the default principle (DP) can function as a nontheory-based approach to ethical problem solving. It is as though all we are saying here is that the person or team with the higher score wins; we have yet to say what constitutes "scoring."
9. The formal argument would look like this:
  - 1) When there is an asymmetric moral conflict either A has to justify why she is allowed to X or B has to justify why A is not permitted to X.

- 2) "A has to justify why she is allowed to X" entails that, unless there are reasons to justify why she is allowed to X, she is not allowed to X.
  - 3) "B has to justify why A is not permitted to X" entails that, unless there are reasons to justify why B is allowed to prohibit A from doing X, B is not allowed to prohibit A from doing X.
  - 4) B's not being allowed to prohibit A from doing X entails that A is permitted to X.
  - 5) "Unless there are reasons to justify why A is allowed to X, she is not allowed to X" entails that, if A is all by herself, she is not allowed to X unless she can offer a reason to X.
  - 6) It is not true that, if A is all by herself, she is not allowed to X unless she can offer a reason to X.
  - 7) Thus, it is not true that, unless there are reasons to justify why she is allowed to X, she is not permitted to X (5 and 6).
  - 8) Therefore, when there is an asymmetric moral conflict, (3) is true (1 and 7).
  - 9) Therefore, when there is an asymmetric moral conflict, A is permitted to do X unless B justifies why A is not permitted to X (8 and 4). Conclusion (9) is just the DP.
10. The agent may choose in the other direction—"I see that my belief that straight marriage should be permissible but gay marriages should not is logically inconsistent, so I am going to abandon my long-held belief that straight marriages are permissible." In this case, the agent retreats to his or her long-held belief. The fact that some counties in the US have stopped issuing marriage licenses altogether because they don't want to issue marriage licenses to gay couples shows that the retreat option is not that rare or weird.
11. Rawls J. *A Theory of Justice*. Cambridge, MA: Harvard University Press; 1971:46-53.

**Dien Ho, PhD**, is an associate professor of philosophy and healthcare ethics at Massachusetts College of Pharmacy and Health Sciences University (MCPHS) in Boston. His research interests are reproductive ethics, theories of explanation, pharmaceuticals and philosophy, and clinical ethics.

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### **Related in the AMA Journal of Ethics**

[Paradigms, Coherence, and the Fog of Evidence](#), January 2013

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## FROM THE EDITOR

### The Autism Paradox

Through the process of researching this issue, I became fascinated with recent research on neurodiversity as it applies to autism. To oversimplify vastly, neurodiversity is the idea that neurological differences (including autism) are the result of normal variation. In other words, we may be creating pathology where there is none. Should we consider autism a disease? Or is it a variation of normal? This question has been the source of heated debate, with many autism advocates arguing that autism should not be considered a disease or disorder.

As a pediatrician, this is a question I struggle with. I support autism advocacy and the rights of people with autism. I believe we need to adjust our mental framework and see people with autism as more than their diagnoses.

At the same time, I have witnessed—in my professional and my personal life—the devastating effects that profound autism can have on a child and his or her family. Some children are unable to reciprocate love or affection towards their parents or siblings. Others engage in self-harm behaviors, sometimes requiring medication in order to minimize harm to themselves. To me, it is evident that autism is frequently a very difficult experience for families. Dismissing this pain and suffering would be flippant and discourteous to the families who have experienced it.

Yet the argument for neurodiversity is compelling. I will leave the details and the task of persuasion to the excellent authors who have contributed to this issue, but I will say this: in my opinion, there are two truths here. First, autism can be devastating; and second, autism is not a disease. These truths exist in uncomfortable tension and may seem contradictory. It can be a complex and awkward stance for a pediatrician when the *DSM-5* specifically categorizes autism as a disorder.

But complexity is not a drawback. Complexity encourages us to consider the ethical dilemmas autism unveils: questions of autonomy, decision making, and intrinsic worth. It forces us to question the assumption that people with autism can't speak for themselves and to carefully balance the need for treatment with the respect for the person. Complexity asks us to weigh the risks of diagnosis with the benefits that may come from the empowerment that knowledge can bring.

To be clear, acknowledging this complexity does not discourage the treatment of autism when medically appropriate. As a medical community, we know that there are treatments for autism that can be effective for many. Recognizing the principle of neurodiversity does not negate the validity or necessity of treatment. Nor does it imply that these treatments should not be fully funded and supported. Rather, it means being mindful about the goals of our interventions and continuing to respect the personhood of people with autism when we consider which treatments to pursue.

It is now estimated that 1 in 68 children has an autism spectrum disorder (ASD) [1]. The diagnosis of autism increased 57 percent between 2002 and 2006 [2] and continues to trend upward. It is clear that these questions are not going away. Now is the time to evaluate our understanding of autism critically, and I thank all of our contributors for their efforts toward this goal.

I would also like to thank several special contributors for this issue. During the process of researching for the journal, I came across a book entitled *Drawing Autism*. This fantastically creative book highlights works of art by individuals with autism, several of whom were generous enough to share new works with this journal. We are proud to exhibit the work of these talented artists and hope that this will further our goal of promoting discussion during Autism Awareness Month.

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## Kathleen K. Miller, MD

PGY-1  
Department of Pediatrics  
University of Wisconsin  
Madison, Wisconsin

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## ETHICS CASE

### Conflicts in Family-Centered Pediatric Care for Patients with Autism

Commentary by Jeffrey P. Brosco, MD, PhD

Dr. Woods entered the patient exam room to meet with 6-year-old Kari and her mother. In her hand, she held the report from Dr. Hoffman, the developmental pediatrician Kari had seen two months ago, which confirmed a diagnosis of moderate to severe autism. After greeting Kari and her mother, Dr. Woods began, "I see Dr. Hoffman started Kari on guanfacine for some of her symptoms and had some recommendations for therapy."

"Yes," Kari's mother said, her voice unsteady. "She wanted us to start going to these therapists for speech and behavior and all kinds of things. And we saw a social worker, and she's going to help us with the paperwork to get it all paid for. And Kari has started the guanfacine."

"This all sounds good," Dr. Woods said gently. She knew guanfacine was the first-line treatment for irritability associated with autism, often prescribed for young children because of its low profile of side effects.

"It's just—" Kari's mother began to cry. "The guanfacine doesn't seem to be helping. In fact, I think she's getting worse. She's angry all the time, and she has these temper tantrums...I don't know what to do."

"What about the behavioral therapy?" Dr. Woods asked.

"I can't manage all these appointments. I just can't. I'm a single mom, I have two other kids, I work—there's no way I can go to all of these. I don't have anyone in town here to help me, and I can't be missing work to drive Kari to appointments every day and doing all this therapy. I know she said it's the best option for Kari, but I have to tell you, it just isn't going to happen." Looking at Dr. Woods, she added, "Don't get me wrong, I love my daughter and I would do anything for her. But to take care of all my kids, I have to work. Look. I read the pamphlets. I know there are other medications that could help. Couldn't we just try one of the stronger medications—the antipsychotics, maybe, they're supposed to help, or an antidepressant—just something that would help her calm down and make her life more manageable..." She trailed off.

Dr. Woods hesitated. While guanfacine was relatively benign, there were significant side effects associated with atypical antipsychotics, and she wasn't sure how comfortable

she was prescribing a strong psychiatric medication when behavioral therapy hadn't been attempted.

"I know it's not ideal," Kari's mother said. "But isn't it better than nothing?"

### **Commentary**

There are several keys to resolving the ethical issues in this case: distinguishing between refusals and requests, acknowledging conflicts between family-centered care and evidence-based medicine, and meeting the obligation to manage emotions and communicate effectively.

### **Refusals versus Requests**

The practice of medicine in the US has changed dramatically in the past 50 years. Until the mid-twentieth century, it was common practice for physicians to assume the role of decision maker for their patients. Following the principle of beneficence, physicians routinely chose among treatment options—including no treatment—depending on what they thought was in the best interest of their patients. Broad social changes, including the civil rights movement, feminism, and anti-Vietnam War protests, shifted the balance away from traditional sources of authority toward empowering individuals. By the 1990s, the idea of patient autonomy was central to medical practice; physicians felt an obligation to tell patients the truth, obtain informed consent to treat, and respect patients' decisions even if they led to seemingly poor health outcomes. Our society now believes that an individual can validly refuse treatment as long as three conditions are in place: (1) the patient is provided adequate information about risks, benefits, and alternatives; (2) the patient has the capacity to understand and appreciate the consequences of his or her decisions; (3) the patient is not unduly influenced by outside forces [1].

In contrast to valid refusals, patient requests need not be honored. A patient may ask for antibiotics, but, if the physician determines that the cause of a patient's upper respiratory symptoms is a virus, he or she is under no obligation to provide a prescription. Even in this era of patient autonomy, physicians retain the authority to determine the range of clinically appropriate actions.

In this case, Kari's mother is making a request for a medicine stronger than guanfacine to help her manage Kari's behavior. Dr. Woods is right to hesitate, given the recommendations of the specialist to start with behavioral intervention. The case is further complicated because Kari is only six years old, which is well below the age when she could make decisions for herself legally. With a diagnosis of moderate to severe autism, Kari is also probably much less able to participate in decisions about her health than other children her age [1]. Dr. Woods has a special obligation to attend to the best interests of her patient.

### **Family-Centeredness versus Evidence-Based Medicine**

In pediatrics, the trend toward respecting patient autonomy has taken the form of “family-centered care.” As articulated in the 2003 American Academy of Pediatrics policy statement on this topic [2], family-centered care “recognizes that the perspectives and information provided by families, children, and young adults are important in clinical decision making.” In addition to respecting the family, honoring cultural differences, and sharing honest and unbiased information, a core principle of family-centered care is “supporting and facilitating choice for the child and family about approaches to care.” Family-centered care is not just a nice idea; research demonstrates it results in improved patient and family outcomes, improved professional and family satisfaction, decreased health care costs, and more effective use of health care resources when a family-centered approach is followed [3].

Even as pediatricians are moving towards family-centered care—and adult physicians are practicing patient-centered care—there is increasing emphasis on the critical importance of using scientific evidence in clinical medicine. Physicians have long based their practice on science, of course, but in the last two decades professional organizations have sought to reduce the gaps between research findings and clinical practice. Clinical practice guidelines, decision-support tools, and health care payment mechanisms are encouraging physicians to base clinical choices on research to ensure all patients receive high-quality care.

Family-centered care and evidence-based medicine are usually not in conflict; most families want their child to receive the most highly recommended, scientifically sound medical care. In Kari’s case, there seems to be significant conflict. Her mother is requesting a second-line medication but not following the recommendation for behavioral interventions that are the primary treatments for children with autism [4]. Although there may not be large-scale randomized trials comparing antipsychotic medications alone to behavioral interventions alone, guidelines for treating the behavioral symptoms of autism start with therapy to improve behavior and communication. Medication alone is insufficient, especially for improving long-term outcomes for patients like Kari [4].

### **Emotions and Expectations**

Patients and doctors make decisions based on emotion as much as on reason. To ignore the emotional aspects of medical practice is to overlook critical professional obligations. In this case, Kari’s mother feels sad, isolated, and overwhelmed; she is probably wondering why Dr. Woods doesn’t seem to want to do what she—the mother—has determined is in the best interest of her child and family. Dr. Woods most likely empathizes with Kari’s mother’s predicament, but may also feel—as many clinicians do when confronted with situations like this—that Kari’s mother should try harder to organize her home situation and start behavior therapy. Furthermore, when patients or

families make requests, physicians sometimes feel that giving in lessens their professional integrity—Dr. Woods’s initial impulse may be to dig in her heels. She may also feel isolated—far from specialist input—and upset that she is required to make decisions about treatment with which she has little expertise or experience.

As the professional, Dr. Woods is obligated to try to recognize her own emotions and use techniques like mindfulness to focus on solving the problem. She should empathize with Kari’s mother, exploring ways to help her feel more supported in fulfilling her responsibilities as a mother and head of household, such as referrals to social work and parent support groups. Finally, Dr. Woods should try to avoid creating an atmosphere in which the mother wants something—medication—that the doctor is withholding. This dynamic is extremely common in everyday medical practice, whether the request is for a medication or a signature on forms, and the clinician needs to reframe the situation to help everyone focus on the problem to be solved: in this case, the new framing is how best to achieve their common goal—helping Kari improve her symptoms and behavior. It is not about whether Dr. Woods will “give” Kari’s mother the prescription [5].

### **Resolution**

As suggested above, the procedure for resolving these sorts of dilemmas begins with the physician exploring and acknowledging the mother’s position, refocusing the discussion on identifying the goals of treatment, and pledging to work with the mother to reach them: “I understand that you are feeling overwhelmed by all your responsibilities, and I can only imagine how difficult this must be. You obviously love your daughter and want the best for her, and right now her temper tantrums are a big problem for you and your family. Let’s figure out the next best step” [6].

Dr. Woods should then review with Kari’s mother the risks, benefits, and alternatives of the various treatment options. How best to do this is, of course, the art of medicine. There are significant side effects with antipsychotics, but there are also dangers to inadequately intervening to prevent temper tantrums, especially as Kari gets older and stronger. Dr. Woods needs to help Kari’s mother understand that the behavior and communication therapists will help her—Kari’s mother—know what to do when Kari gets angry, and better still how to prevent the tantrums, and that they can come to her home. In the long run, this will be good for the whole family. If Kari’s mother remains firm in her demand for a short-term remedy, Dr. Woods may offer a compromise: “I’m concerned about starting an antipsychotic because of the potential side effects, but I also understand your point of view. How about we arrange for a therapist to come to your home for an hour a day to work with you on behavioral techniques, and we’ll use risperidone as a temporary measure until you feel more comfortable with managing Kari’s tantrums?”



Ultimately, Dr. Woods should respect Kari's mother's decision. There are significant risks to denying Kari's mother's request for medication: Kari's behavior will probably worsen, affecting her learning, peer relationships, and family function. Children with significant developmental disabilities are at high risk for both accidental and nonaccidental trauma [7, 8]. Although not ideal, risperidone is not completely inappropriate in this clinical scenario. (It's not like prescribing antibiotics for a viral illness, for instance.) Kari's mother is going to have to live with the decisions made about Kari's treatment, most likely for a lifetime, and as such is in the best position to make judgments about imperfect choices.

Dr. Woods should document her conversation with Kari's mother in the medical record, of course, and continue to follow Kari closely. If Dr. Woods feels unable to prescribe an antipsychotic medication, she should locate a physician who can. Communicating with the developmental pediatrician is also critical and may allay some of Dr. Woods's concerns about the medication. If over time Kari's mother is truly unable to meet her daughter's medical needs, Dr. Woods will have to consider whether to involve the child welfare system.

Treatment requests made by caring, involved families should routinely be honored when consistent with evidence about safety and efficacy. The physician's role is to outline appropriate options and help the family choose the approach that best matches the scientific evidence with the family's values. When there is doubt, a clinical ethics consultation can be helpful in analyzing the issues in a specific case.

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**Jeffrey P. Brosco, MD, PhD**, is a professor of clinical pediatrics and associate director of the Mailman Center for Child Development at the University of Miami Miller School of Medicine and chair of the Pediatric Bioethics Committee at Jackson Memorial Hospital in Miami, Florida. Board-certified in pediatrics and developmental-behavioral pediatrics, he completed his tenure as a Robert Wood Johnson Generalist Faculty Scholar in 2003 after earning an MD and a PhD in the history of medicine at the University of Pennsylvania. With Diane Paul, he co-authored *The PKU Paradox: A Short History of a Genetic Disease* (Johns Hopkins University Press, 2013). Dr. Brosco's research includes analysis of the history of health care for children in early twentieth-century Philadelphia, the historical epidemiology of intellectual disability, and the history of newborn screening in the US.

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# AMA Journal of Ethics

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## ETHICS CASE

### **Autonomy and Autism: Who Speaks for the Adolescent Patient?**

Commentary by Rebecca Benson, MD, PhD, and Catherina Pinnaro, MD

Jake was diagnosed with autism at the age of four. His symptoms were treated with behavioral therapy until the age of 14, when he began having frequent angry outbursts. He often shouted at his parents and had fits of screaming, occasionally at school. At the time, his mother noticed that he was very irritable and often seemed depressed. He was prescribed an SSRI and an atypical antipsychotic for his outbursts and mood symptoms.

Now 17, Jake has cognitive abilities in the low-normal range, but his ability to perform daily activities is more substantially impaired, and his mother is heavily involved in his care. He needs reminders and supervision to care for himself, including taking his medication and doing his homework, and refuses to brush his teeth or hair unless his mother insists. He experiences sensory overload. He attends an alternative high school because of his repeated angry outbursts at school and difficulties paying attention.

His physician, Dr. Mullins, greets Jake and his mother cheerfully at Jake's check-up. "How have things been going?" she asks.

Jake resentfully stares at the wall behind her. "I'm not going to take this stupid medicine anymore," he says. "I hate it. I hate taking it every day."

His mother adds to the conversation. "He does," she confesses. "But it really does make a difference. When we tried to go off the meds a year ago, Jake was out of control. He screamed at his little sisters whenever they spoke to him, he got in trouble at school; he was just difficult. When he takes his meds—and I make sure he takes them every day—he just seems less irritated and annoyed. He doesn't have these outbursts; he does better in school. I hate making him take medication, but I just can't imagine trying to take care of all my kids when Jake is as volatile as he was last year."

Dr. Mullins turns to Jake. "What do you think about that, Jake? Do you think the medications make a difference in how you feel?"

Jake doesn't answer right away. Staring at the floor, he says sullenly, "I don't care. It's just for everyone else that I take this medicine. I don't like the way it makes me feel. I don't care if everyone else doesn't want to be around me. I'm sick of it. I'm almost an adult. Why does everyone else get to decide what I do, and I don't get to have any say?"

## **Commentary**

Before addressing the issue of who speaks for the autistic patient, we must address who speaks for the pediatric patient—that is, who makes decisions about whether to accept or refuse treatment (not who advocates for the patient).

### **Minors and Medical Decision Making**

Autonomy is an inherently complicated issue in pediatric medicine. Pediatricians generally expect parents to be responsible for deciding what is in the best interest of their children. This parental authority was derived from common law, the constitutional right to privacy regarding family matters, and a general societal presumption that parents or guardians will act in the best interest of their legally incompetent children [1]. Patients are legally considered minors until the age of 18 in most US states, although some states have exceptions for emancipated minors. Emancipation occurs when something in the child's life—marriage, military enlistment, pregnancy—alters the relationship between the child and parents and supersedes the parent-child relationship [2].

Egregious discrepancies in conceptions of a child's best interest do arise, such as when parents refuse a medically recommended blood transfusion for a critically ill child based on religious principles. These wishes can be evaluated and handled by the judicial system or overridden by physicians in an emergency situation, based on a precedent Supreme Court decision [3]. However, in the majority of circumstances that arise in pediatric medicine, the ultimate decision maker is the parent or guardian.

That being said, the "mature minor exception" is an ethics-derived concept that reflects the belief widely accepted in pediatrics that, as a child grows and develops, his or her cognitive capacity increases substantially so that he or she may merit being treated as an autonomous medical decision maker. Interestingly, this exception is not reflected uniformly in the law. Fourteen states permit mature minors to consent to general medical treatment in either all or a restricted range of circumstances, and three states allow minors regardless of their age or maturity to consent to treatment in all or some circumstances. States' requirements for mature minor exceptions vary and comprise a combination of qualities, including age, ability to meet the informed consent standard (i.e., capacity), maturity, and having graduated from high school [4].

### **The Minor with Autism and Medical Decision Making**

For the purpose of assessing Jake's rights to make his own decisions regarding his medical care, we will evaluate his case using the concepts of "maturity" and "capacity." Maturity as defined by courts takes into account age, level of education, grades in school, disciplinary issues, and future plans [5]. Capacity implies general understanding of one's condition and the risks and benefits of the intervention in question, the ability to communicate a choice, and the ability to reason or think logically [5].

In this particular situation, it appears that Jake's mother has his and the family's best interests in mind. The scenario clearly establishes that the medication is helpful for Jake's mood and his overall daily functioning, including his school performance and familial interactions. After a trial off the medication a year ago, the family reported that he had more moodiness and outbursts, which improved when he began taking it again. His mother is clearly concerned about his ability to have good relationships with others and to do well in school. No matter what state Jake lives in, he currently exhibits neither the capacity nor the maturity to refuse treatment. His level of education and overall daily functioning illustrate that he is not mature enough to make important health decisions unilaterally. Additionally, it does not seem that he understands the risks and benefits of his medications clearly, nor in our scenario does he demonstrate logical thinking about why he does not want to take them. For these reasons and because of his age, he certainly does not have a legal right to make his own decisions regarding his medical care. However, it is appropriate to acknowledge and address his reluctance to take the medication and to engage him in the process of shared medical decision making.

There is no standard of care for treatment of depression or other mood disorders specifically in children with autism, but the current guidelines for treatment of depression in adolescents is to try various SSRIs (fluoxetine and escitalopram would both be approved for Jake) to find one that is effective and has few or tolerable side effects [6]. It is not uncommon for patients to report that they do not like the way an SSRI makes them feel, and changing to another SSRI may allow them to find a medication that is equally effective without the unpleasant effect. Dr. Mullins certainly should explore this issue further. There are many SSRIs and atypical antipsychotics on the market, and there may be a medication that is better suited to Jake's symptoms and that has a more favorable side effect profile. Jake's mother also indicates that he does not remember to take his medicine every day. Risperidone, an atypical antipsychotic, comes in a slow-release depot formulation that he would not need to take every day [7].

### **Long-Term Goals**

The ultimate goal should be to recognize Jake's impairment but maximize his autonomy, helping him to develop as much maturity and independence as he is capable of. This is best accomplished by listening closely to his preferences and offering options that address his concerns (e.g., finding medications that don't have unpleasant side effects). At the same time, this process of shared decision making empowers his parents to protect him from making choices that may have a negative impact on his health and overall well-being, in this case by prioritizing the goals of school success and maintaining good relationships. This process might be aided by engaging the family in formal shared decision making (SDM). The process of SDM as summarized by the Center for Mental Health Services includes several steps that may help facilitate a discussion among the

involved parties. These include identifying preferences, negotiating options/concordance, and sharing the decision [8].

Medical evaluation and decision making in Jake's case become less clear cut when he reaches the age of majority. A transition-to-adulthood evaluation should be initiated soon to ease the burden on both Jake and his parents. Autism Speaks has a free transition kit to help adolescents move into adulthood, including information about health, education, and legal matters [9].

One option for Jake's parents would be to apply for guardianship, which would grant them the legal authority to make medical decisions for him even after he reaches the age of majority [10]. They may consider this option if Jake continues to demonstrate poor ability to understand his condition, reason through the risks and benefits of treatment options, and understand the implications of his choices. This could be frustrating for Jake, but it would protect him from the potential poor health and emotional outcomes that could arise from incomplete understanding of the ramifications of proposed treatments or therapies. On the other hand, by participating in the process of shared decision making, Jake may progress to a level of maturity over time in which he demonstrates capacity to make his own health care decisions, with support from others when needed.

Optimizing Jake's medications and allowing him to actively participate in the discussion of his treatment is a good way to ensure that everyone is on the same page. Like any other patient old enough to have opinions about his treatment plan, an autistic patient should be allowed to articulate his or her needs and treatment goals. Both the clinician and his family or the facility involved should take these statements seriously, and all parties should work together to collectively do what is best for the patient.

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**Rebecca Benson, MD, PhD**, is the medical director of the Pediatric Pain and Palliative Care Program at the University of Iowa Children's Hospital and the director of the ethics consult service at the University of Iowa Hospitals and Clinics in Iowa City. She is passionate about providing support to children and families experiencing serious illness and educating health care professionals about palliative care and ethics.

**Catherina Pinnaro, MD**, is a pediatric resident at the University of Iowa Hospitals and Clinics in Iowa City. She plans to pursue fellowship training in medical genetics. Her research interests include ethical issues associated with clinical exome sequencing and reporting of incidental findings.

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## ETHICS CASE

### Communicating Concern about Early Signs of Autism to Parents

Commentary by William D. Graf, MD

Dr. Peterson smiled at Elizabeth, a 15-month-old who was in his office for her well-child check. He made small talk with Elizabeth's mother for a few minutes while Elizabeth played with a doll from the exam room's toy chest.

"Do you have any concerns today?" he asked the mother.

Elizabeth's mother smiled. "Not really," she said. "She's been a little slow to talk—her brothers were both talking much more at this age—but I think she's catching up."

Dr. Peterson noticed that Elizabeth was flapping her hands slightly. "Does she do that often?" he asked the mother.

"Oh, once in a while."

He continued to observe Elizabeth play as he asked her mother a series of questions. Elizabeth continued to flap her hands throughout the interview. To Dr. Peterson, it looked like "stimming," or self-stimulation, behavior that is frequently associated with autism. Elizabeth had poor eye contact, although she did respond to her name and come to her mother's side when called. She also rocked back and forth on her knees, singing to herself lightly. The hand-flapping, rocking behavior, and poor eye contact gave Dr. Peterson reason to consider autism.

He hesitated. According to Elizabeth's mother, Elizabeth had met all of her developmental milestones, although recently it seemed that her speech development was not on track. There were plenty of signs that she could be developing normally: she played with the doll attentively and demonstrated affection toward it, she responded to her name, and was well-behaved. Her mother—who had two older children—hadn't noticed anything out of the ordinary.

Dr. Peterson considered his course of action. He knew that Elizabeth would undergo routine screening for autism at her 18-month visit and didn't feel that he saw anything severe enough to warrant an extensive evaluation at the moment. However, he wondered if Elizabeth's mother had a right to know that he was concerned. He was apprehensive that conveying his concern to the mother involved a certain degree of



unnecessary risk: it would mostly likely cause increased anxiety for the family and possibly spur Elizabeth's parents to perceive normal behavior as pathology. But did he have an ethical obligation to share his concerns with her mother?

### Commentary

In this vignette it is evident that Dr. Peterson is an excellent and caring clinician. He understands his ethical obligations to act in the best interests of his patients with possible neurodevelopmental disorders. Dr. Peterson wonders about the option to initiate an early intervention program for Elizabeth now, before moving on to see his next awaiting patient. It would not be controversial to help arrange for an early intervention program that provides a free neurodevelopmental assessment for children between birth and age 3 under United States federal law (Public Law 99-457).

But a conscientious clinician like Dr. Peterson recognizes the complexity of the developing brain, the difficulty in diagnosing behaviorally defined neurodevelopmental disorders in infancy, and the controversies surrounding several biomedical and behavioral treatments proposed for autism. Such a clinician is appropriately concerned about the process of providing accurate and unbiased information. He or she understands the limitations of basic and clinical neuroscience and the value of evidence-based medicine. Such a clinician is aware that the influential fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* merged all autism disorders into one broad categorical diagnosis of autism spectrum disorder (ASD), which validates the classification of younger children with milder, nonspecific neurodevelopmental differences as "on the spectrum."

More importantly, such a clinician knows that ASD is a dimensionally defined category of heterogeneous neurodevelopmental disorders that result from genetic and epigenetic influences during fetal brain development [1-3]. With this in mind, it is clear that *postnatal* neurodevelopmental screening is more about the recognition or *detection* of prenatal-onset neurodevelopmental disorders than it is about the *risk of acquiring* a neurological disorder or disease. Acting on concerns about autism in a young child such as Elizabeth may cause harm through pathologization—labeling atypical behavior or mild neurodevelopmental differences as a neurodevelopmental disorder—which might generate emotional and financial stress for the family without any guarantee of improving outcome.

Dr. Peterson has the luxury of using the diagnostic "test of time" principle while providing support and guidance to Elizabeth's parents. As an experienced physician, Dr. Peterson may not always know what is best for an individual child and family, but he can gently express some concern now and see Elizabeth and her parents back for re-assessment in a few weeks.

How he expresses that concern has great potential to shape the family's response and, therefore, Elizabeth's life. Thus, for Dr. Peterson to describe autism as a grave condition would be more upsetting to the parents than calm explanations that autism is not a disease, and not necessarily a disorder, and that they might be beginning to discover traits of Elizabeth's nature. Without this kind of framing, even preliminary concerns about autism are likely to cause parental guilt and anxiety. Autism invokes more child stigmatization than other developmental diagnostic labels (e.g., developmental language delay) [4]. A clinician like Dr. Peterson understands that the more stress any parent feels about the diagnosis, the more impaired he or she will judge the child to be [5]. Giving parents early support and reassurance to love their children as they become their unique authentic selves might be the best way to create a "therapeutic alliance" and promote parental acceptance [6]. In addition, caregivers need not try to change many behaviors and stereotypes associated with autism—especially those behaviors that are not a burden to the child [7].

### **If Elizabeth Does Have Autism: Principles in Autism Treatment**

If Elizabeth is later diagnosed with autism, Dr. Peterson should observe certain principles.

*Involve parents in an active shared decision making partnership.* In her 2010 commentary in this journal (formerly known as *Virtual Mentor*), Margaret Moon, MD, presents a bioethics approach to an autism-treatment dilemma based on the four traditional principles of medical ethics (respect for autonomy, beneficence, nonmaleficence, and justice) and concludes that optimizing a therapeutic alliance between the physician and the family (also known as a "shared decision making" model) would lead to the best outcome—promoting a child's short- and long-term well-being [8]. Respecting parental authority and following a shared decision-making partnership with Elizabeth's mother would be a particularly sensible approach for Dr. Peterson given Elizabeth's good hearing ability, social skills, and young age. The most important reason to establish a shared decision-making partnership with Elizabeth's parents is to promote their involvement in interventions for her. Ivar Lovaas, one of the pioneers of behavioral therapies for autism, has emphasized that parents and other family members should participate actively in teaching their child at home to reinforce the learning activities initiated in formal special education and therapy programs in schools and clinics [9].

*Make sure to focus on effective treatments.* The 75-year history of autism has included numerous controversies and pseudoscientific abuses that have harmed children and their parents (see table 1). It is vital that physicians and parents focus on seeking out treatments that good evidence shows to be safe and effective.

**Table 1.** A history of conceptions about causes of and treatments for autism

Era	Theory and Practice
Prior to 1940s	Most children with autism are described as emotionally disturbed, schizophrenic, or psychotic. School or community services are generally unavailable. Children are vulnerable to institutionalization and other harms [9, 10].
1943	Kanner publishes a landmark study of 11 children with “autistic disturbances of affective contact” and proposes its diagnostic criteria. Kanner describes the parents of autistic children as highly intelligent but unsociable, detached, and lacking in warmth. Later, Kanner denies these viewpoints [11].
1960s	Bettelheim, a specialist in the treatment of children with autism with the Orthogenic School in Chicago and author of the book, <i>The Empty Fortress: Infantile Autism</i> , builds a reputation as a specialist in the treatment of children with autism, declaring it an emotional disorder because of psychological harm caused by their mothers—further propagating the “refrigerator mother” theory through the mainstream media [12].
1960s	Rimland’s <i>Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior</i> challenges the psychiatric orthodoxy about the unloving-parent theory in autism [13]. Rimland believes the causes of autism to be biological and postulates that it is related to weak immune and digestive systems, environmental pollutants, antibiotics, and vaccines containing traces of mercury. Rimland creates the Autism Research Institute (ARI) and supports the Defeat Autism Now (DAN!) approach to treatments for autism such as vitamin supplements (e.g., high-dose pyridoxine with magnesium) and restriction diets (gluten- and casein-free), some of which are harmful and some of which are ineffective [14, 15].
1970s-1990s	Lovaas and others report clinical improvement of some children receiving intensive behavioral interventions for autism. Some behavioral approaches of the 1960s and 1970s, involve aversive or restrictive interventions, the use of which is strongly criticized in later years [16].
1997	Pollak publishes <i>The Creation of Dr. B</i> , discrediting Bettelheim and describing how he exaggerated his credentials and expertise on autism, abused the children under his care, terrorized parents, and popularized the destructive “refrigerator mother” theory without adequate proof [17].
1998	A fraudulent research publication by Wakefield et al. claims an association between the measles, mumps, and rubella (MMR) vaccine and autism and bowel disease [18]. This event causes public misperceptions, undermining immunization practices and threatening both individual and public health [19].

mid-1990s to mid-2000s	Defeat Autism Now! (DAN!), one of the more prominent advocates for the now medically discredited belief that vaccines may be a cause of autism, advocates for alternative treatments for autism and maintains registries of doctors trained by the program to perform them. Its “highest rated” autism treatment is chelation therapy, which involves removing heavy metals from the body. Chelation therapy is considered scientifically unfounded and an unethical practice for children with autism [20]. An estimated 2 to 8 percent of children with autism at this time receive chelation therapy due to the false belief that mercury or other heavy metals cause autism symptoms [21]. A five-year-old boy with autism dies of hypocalcemia related to IV sodium ethylene diamine tetra-acetic acid chelation therapy in a Pennsylvania physician’s office [22].
2010s	Many intensive behavioral interventions for autism (e.g., applied behavior analysis, or ABA) are controversial and polarizing therapies in the “autism community”—effective for some families but ineffective, demanding, and exorbitantly costly for other families. ABA-based methods (such as discrete trial training, pivotal response training, and teaching functional routines) may be effective in improving adaptive behavior, language, and socialization in some children with autism [23, 24]. Nevertheless, given the state of the evidence about their effectiveness, claims of “cure” and “recovery” from autism produced by ABA are misleading [25, 26].
2015	Refusal to vaccinate children for fear that certain vaccines may cause autism leads to several outbreaks of measles, a disease previously all but eradicated, in the United States [27].

*To be just, treatments must be equally distributed and cost-effective.* The first three core medical ethics principles (i.e., respect for autonomy/parental authority, benevolence, and nonmaleficence) pertain to individual care—ethical quandaries involving a particular physician providing care to individuals or specific families. In contrast, the fourth core ethics principle, justice, involves equity in resource allocation. The principle of justice stipulates that health care resource allocation satisfy two fundamental criteria—equity and making the most health care possible available to the most people, cost effectiveness.

As for equity, it is uncertain whether Elizabeth currently lives in a US state or Canadian province that has passed either legislation providing persons with autism a guaranteed right to intensive behavioral interventions or mandates requiring private health insurers to offer extensive coverage of autism behavioral therapies. Thirty-seven of 50 states mandate some level of health coverage for autism therapies [28]. Laws of this kind are one important way to ensure that everyone with autism has the same acceptable level of access to treatment.

Ultimately, to ensure widespread access to treatment in the long term, we must prioritize finding and providing cost-effective interventions. The public will need to continuously debate how to allocate and pay for a wide range of medical therapies and special educational services, and using those with the greatest cost effectiveness will make more resources available to achieve other goals. ABA programs, which are, as mentioned above, variably effective, cost between \$10,000 and \$100,000 per child annually [29, 30]. Studies show that early intervention programs have benefits for a wide range of children, including poor inner-city children without neurodevelopmental disorders [31]. Diversion of enormous amounts of resources to some ineffective or unnecessary treatments for children with one particular condition makes it less likely that children with other needs will receive services or resources.

### Conclusion

Just as there is no accepted single path to human flourishing and authenticity in typically developing children, there is still no perfect standard for raising and caring for a child with atypical neurodevelopment. Early recognition of children with special needs requires a therapeutic alliance with parents during their efforts to find the right medical and educational approach for their children and their families.

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**William D. Graf, MD**, is professor of pediatrics (neurology) and neurology (child neurology) at Yale School of Medicine in New Haven, Connecticut. Dr. Graf is the chair of the Child Neurology Society (CNS) Ethics Committee and an active member of the American Academy of Neurology (AAN) Ethics, Law, and Humanities Committee. His clinical and research interests focus on all aspects of brain development.

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## MEDICAL EDUCATION

### Autism Education in Residency Training Programs

Nili E. Major, MD

Autism spectrum disorder (ASD) is a neurodevelopmental disability characterized by deficits in social communication and the presence of restricted and repetitive behaviors. The term ASD describes a behavioral phenotype that varies considerably from person to person and results from heterogeneous etiologies. In recent years, there has been much attention focused on ASD by the medical community, media, and general public, in large part due to the steadily increasing prevalence rates [1]. The most recent data published by the Centers for Disease Control and Prevention (CDC) in 2014 estimate that approximately 1 out of 68 children in the US has an ASD [1]. Although there is ongoing debate regarding the factors contributing to this increase, there is clearly a need for more health care professionals who are knowledgeable about ASD. Pediatric primary care clinicians, in particular, play a critical role in the identification and treatment of children with ASD and must be appropriately trained in the care of such children.

Recent studies exploring parent and clinician experiences of primary care for children with ASD have revealed dissatisfaction on both sides. Parents of children with ASD have reported poor access to a medical home, delayed referrals for evaluations, inadequate counseling about treatment options, lack of clinician knowledge regarding community supports and services, and limited confidence in their physician's ability to provide a high level of care [2, 3]. In surveys, practicing pediatricians have indicated the inadequacy of training in developmental and behavioral pediatrics (DBP) during their residency years [5, 6] and pediatric primary care clinicians have reported feeling ill-prepared to meet the needs of their ASD patients in particular and express a desire for further ASD education and training [2-4]. In a more recent study conducted by this author and colleagues (described further below), the majority of pediatric residents surveyed reported that ASD education was important to their careers, but more than half described the quality of their autism training to date to be "fair" or "poor" [7].

#### The Autism Case Training Curriculum

"Autism Case Training (ACT): A Developmental-Behavioral Pediatrics Curriculum" was designed by faculty and fellows from DBP programs with the purpose of educating future clinicians on the fundamental components of identifying, diagnosing, and managing ASD through real-life scenarios [8]. It has undergone internal and external peer review and extensive piloting and been endorsed by the American Academy of Pediatrics (AAP) [9]. This curriculum was developed as part of a collaboration between



the CDC and the Health Resources and Services Administration's Maternal Child Health Bureau (MCHB).

The ACT curriculum is designed to be highly user-friendly. It consists of seven case-based modules with associated teaching tools, including a facilitator guide and PowerPoint presentations. The facilitator guide includes specific goals and learning objectives for each module, a detailed case, suggested discussion questions and prompts, content for use in answering questions, and relevant handouts. There is an extensive video library available that includes clips illustrating specific teaching concepts—for instance, distinguishing between typical and atypical play in children. There is also a series of videos depicting discussions between experienced clinicians and simulated patients that are particularly useful in teaching communication skills. The seven modules are: Early Warning Signs of Autism, Screening for Autism, Communicating Concerns: Screening and Diagnosis Results, Making an Autism Diagnosis, Early Intervention and Education, Treatments for Autism, and Autism-Specific Anticipatory Guidance. All curriculum materials, including the videos, are available on the CDC website and can be downloaded free of charge [8]. There is also a shorter, self-guided module that can be completed to earn continuing education credit [10].

### **Evaluating the ACT**

Following publication of the curriculum in 2011, we conducted a study at pediatric residency programs across the US to evaluate its implementation and short-term efficacy [7]. Curriculum modules were mailed to 33 training programs; 26 sites returned the study forms. The facilitators, who were either faculty or fellows in DBP, were expected to facilitate one teaching session at their institutions using an ACT module and to return the study forms to the investigators.

*Participants.* Data were obtained from 191 learners. Of these, 114 were pediatric or medicine-pediatric residents, who were the focus of the study. (The remainder were primarily medical students.) The median number of learners present during a session was 4, with a range of 1-30.

*Method.* One of the seven curriculum modules was randomly selected and mailed to the participating facilitator along with pre- and posttests and a facilitator evaluation form. Pretests were completed immediately before the teaching sessions, 68 percent of which were conducted during the DBP rotation; the rest took place at other times, such as during general house staff conferences. The duration of the sessions ranged from 20-90 minutes, with a mean of 60 minutes. Immediately after the teaching session, learners completed the posttests. Facilitators then completed the evaluation form and returned the materials to the investigators.

*Materials.* Pretests included multiple-choice questions regarding learner demographics, baseline attitudes towards ASD education (as reported above), and knowledge-based, module-specific multiple-choice questions. Posttests included the same knowledge-based questions. After the module, participants were asked to retrospectively self-assess their perceived knowledge and proficiency related to the module goals and objectives both before and after the session using Likert-style ratings.

*Results.* The data were analyzed using *F* and *t* tests. Average pretest scores did not vary by year in training ( $p = .38$ ) or how residents rated the quality of their training to date ( $p = .64$ ) [7]. The mean score on the knowledge-based pretests for all modules was 58.6 percent and the mean score on the posttest was 75.3 percent; the average gain was 16.7 percent ( $p < .001$ ).

Self-assessments of residents' knowledge and proficiency were measured on a 4-point Likert scale (1 = poor, 4 = excellent). On the premodule assessment, average ratings did not vary significantly by year of training ( $p = .32$ ) or career plans ( $p = .12$ ). The mean premodule assessment score was 2.26 and the mean postmodule assessment score was 3.08, with an improvement in mean scores of 0.82 ( $p < .001$ ). The majority of study facilitators (97 percent) reported that the learners were "engaged or very engaged" during the teaching sessions [11]. And "ninety-four percent of residents rated the session as useful or very useful to their training" [12].

Overall, we found the curriculum to be well received, able to be implemented with a wide range of learners and varied session durations, and associated with some positive short-term changes in knowledge and self-perceived competence. An unexpected, and concerning, finding was that performance on the pretest knowledge-based questions, as well as the self-assessments of competence, did not improve with training year. This finding speaks to the inadequacy of autism education in residency.

The study's primary limitation was that it only assessed short-term changes in knowledge and perceived competence following a single, brief teaching session. Furthermore, due to sample size limitations, we were unable to conduct analyses to determine if particular modules or session characteristics affected outcomes.

### **The Future of Autism Education**

Pediatric primary care clinicians have made it clear that there is a need for improved education in residency training about ASD and other developmental and behavioral disorders. The development of teaching tools such as the ACT curriculum and a variety of other excellent resources (e.g., the AAP Autism Tool Kit and the Autism Speaks/Autism Treatment Network tool kits) is one important step towards better preparing the physicians who will care for children with ASD [13, 14]. However, these resources will only be effective if adequate time is devoted to teaching residents about developmental

and behavioral disorders during training. In 1997, the Accreditation Council for Graduate Medical Education (ACGME) mandated a one-month rotation in DBP, although in most programs residents typically spend less than a month on the rotation due to vacation days, on-call duties, and work-hour restrictions [15]. In 2013, new ACGME requirements specified that the experience in DBP should consist of one education unit, defined as 32 half-days, which can be completed in a block rotation or longitudinally [16]. It is unknown how this new requirement is currently being implemented and adhered to in training programs.

Improving autism education in the face of limited time and competing priorities in training requires a strong commitment on the part of graduate medical education leadership both nationally and locally. Faculty time must be appropriately supported for teaching during the DBP rotation and in other settings, such as resident continuity clinics. Innovative approaches to the DBP educational requirement, such as longitudinal structuring, should be explored. Finally, it should be noted that efforts to improve autism education should not be limited to pediatric residency training. To ensure high quality care for people with ASD across the lifespan, we must also consider continuing education for practicing pediatric clinicians, autism education during medical school, and training for internal medicine residents and adult primary care clinicians.

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**Nili E. Major, MD**, is a developmental-behavioral pediatrician at the North Shore-LIJ Cohen Children's Medical Center in New Hyde Park, New York. Her professional interests include resident education in developmental-behavioral pediatrics.

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## IN THE LITERATURE

### **On Risks and Reality: Communicating the Difference between Autism Risks and Diagnosis**

Matthew A. Rysavy and Jody R. Murph, MD, MS

**Rossi J, Newschaffer C, Yudell M. Autism spectrum disorders, risk communication, and the problem of inadvertent harm. *Kennedy Inst Ethics J.* 2013;23(2):105-138.**

One of the scariest parts of raising a child is the sense of not having control, of not knowing what is coming or what to do about it. We want the best for our children; we want them to be healthy and safe, and we do not want to make mistakes. So, having information about what might be expected—on the likelihood of certain conditions or diseases, for instance—should provide some relief. But does such knowledge also have a downside?

Rossi et al. [1] explore this issue in the context of communicating with parents about risk of autism. As a student of medicine and epidemiology and a general pediatrician, we found that their article raised many points relevant to our work.

It is important to distinguish between risk and diagnosed disease. Hearing a bump in the night might lead you to suspect that there is a mouse in your house—but a bump is not the same as an actual mouse. In the same way, risk indicates an increased probability of some condition or disease—but risk is not the same as a real diagnosis.

Risk and diagnosis are related: risk increases the likelihood of a diagnosis. Moreover, diagnosed disease may lead to increased risks for another condition (the presence of a mouse may increase the likelihood that other critters entered where the first one did). However, the concepts of risk and diagnosis remain distinct—the difference being that risk information, by definition, reflects uncertainty.

Rossi and colleagues point out that, because of such uncertainty, information about autism risk may sometimes cause harm to families by: (1) arousing unnecessary fear or anxiety, (2) blaming or stigmatizing parents and children, and (3) leading families to take actions that are not in their best interests. This last harm may occur when families pursue unnecessary—and sometimes invasive and costly—therapies and diagnostic interventions or avoid potentially beneficial ones.

The recent controversy about a purported link between the measles-mumps-rubella (MMR) vaccination and autism demonstrates the potential for all of these harms. Research linking MMR vaccination to autism [2] led many parents to be fearful, feel guilty, and take actions not in their children's best interests. Although the research that incited this controversy was later discredited [3, 4], it is easy to see how similar harms may occur even when research findings are well supported.

Rossi and colleagues also point out that knowledge about risk of autism may alter how children view themselves and how others view them. The authors suggest that merely having risk factors (characteristics believed to confer an increased risk) for autism—even in the absence of an autism diagnosis—may result in children being “placed under a microscope” and in otherwise normal behaviors being judged as problematic [5]. Such harms may occur when probabilistic risks are conflated with an actual diagnosis—when the possibility of a condition is confused with the condition itself.

Reading about the possible negative effects of risk communication that Rossi and his colleagues describe, we are left to wonder how such harms can be avoided. Specifically, what can we, as clinicians and trainees, do to avoid them?

There seem to be an almost infinite number of scientific studies, educated opinions, uneducated opinions, interpretations, and manipulations of autism risk information available to families. Unless families decide to avoid media altogether—newspapers, magazines, television, and the Internet, including Facebook and Twitter—they are likely to be exposed to information about autism risk. Consider the headlines that we have seen during the previous month alone:

- “Risk of Autism Goes Up with Older Parents (Especially Moms)” [6]
- “Antidepressant Use in Pregnancy Tied to Autism Risk in Boys” [7]
- “Low Maternal Thyroid Raises Autism Risk” [8]
- “Families with One Autistic Child Face 10-Fold Risk of Another Autism Spectrum Disorder-Diagnosed Child” [9]
- “Fluctuating Lipid Levels during Pregnancy Increase Autism Risk in Children” [10]
- “Father’s Obesity Tied to Child’s Risk for Autism” [11]
- “No Link between Inducing Labor and Risk Of Autism” [12]

This list only scratches the surface of what families are exposed to.

To prevent the harms identified by Rossi and colleagues, individuals involved in conducting and disseminating autism research have a responsibility to avoid inflating the validity or importance of their work. Clinicians and trainees who engage in research at various stages of their medical careers may face pressure to conduct hasty analyses or to overextend the real-world significance of their findings. Concerns about funding or promotion or the desire to bolster a resume may conflict with producing research that is in the best interest of families. Researchers should remember that they make important

ethical choices when selecting research methods, interpreting their findings, and publishing their results.

Those of us not directly involved in autism research can educate families about the important distinction between risk and diagnosis. We can help families understand risk as something that we accept and live with daily, even if we are not acutely aware of doing so. When discussing unfamiliar risks, we can place them in the context of more ordinary risks such as traveling by car—a risk that many of us, every day, weigh against the benefit of getting our families where they need to be. The annual rate of injury from motor vehicles in the US is estimated to be 711 injuries per 100,000 people [13]. But the risk of injury can be modified by driving conditions and car safety features as well as by individual behaviors like wearing a seatbelt. We should be prepared to communicate about risks in a way that the families we serve will understand and that will allow them to make informed decisions.

We also suggest that clinicians and trainees have a responsibility to learn to interpret scientific evidence accurately. The information and misinformation available to families is always changing. In our roles, we are expected to correct misunderstandings based on inaccurate data as well as to help families identify good sources of information. There is no aspect of medicine that clinicians are permitted to practice without demonstrating significant competence. Interpreting research evidence—something clinicians in all medical specialties must do regularly—should be no exception.

The reality is that even the best risk information—information derived from observations of large groups—may not precisely meet the needs of the individuals we work with. For an individual at a given time, a condition or disease is present or is not present at a given time; it is 100 percent or 0 percent and never in between. Like learning that tomorrow's weather forecast indicates a 30 percent chance of rain—when what we need to decide is whether to have a picnic, yes or no—disease risk information may not provide exactly what clinicians and families want or need to know to make health-related decisions. Even so, scientifically sound risk information can be useful. It is often the best tool that we have to make sense of uncertainty. We should learn to use this imperfect tool as well as we can.

As Rossi and colleagues point out, confusion stemming from risk communication has real consequences. Much of what families hear about risks they hear outside of the clinic; yet, there is still much that clinicians and trainees can do. Those of us involved in research should consider families' interests when conducting and publishing our work. In clinic, we should always be clear with families about the difference between risk and diagnosis. Moreover, by helping families to distinguish between good information and nonsense, we can support their ability to make informed decisions and avoid unnecessary worry. Parenting may still be scary. But it does not need to be misinformed.

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**Matthew A. Rysavy** is a medical student and PhD candidate in epidemiology at the University of Iowa Carver College of Medicine in Iowa City, where he is active in the design and implementation of the evidence-based medicine curriculum. His interests include child health, research methods, and science education.

**Jody R. Murph, MD, MS**, is an associate professor of pediatrics at the University of Iowa Children's Hospital and has secondary appointments in the College of Public Health, the Department of Epidemiology, and the College of Law at the University of Iowa in Iowa City. Her interests include vaccine development and controversies, health policy, and the importance of social determinants of health on early child development.

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## HEALTH LAW

### Caring for Patients with ASD and Their Caregivers: Federal and State Autism-Specific Insurance Reform

Annemarie M. Kelly, JD, LLM

*People are always looking for a single magic bullet that will totally change everything. There is no single magic bullet.*

–Temple Grandin, autism reform advocate [1]

“Economic burden,” “regulatory maze,” and “lawyer’s paradise” are a sample of the epithets lobbed against the Americans with Disabilities Act (ADA) before it was signed into law in 1990 [2-4]. A quarter-century later, similar doomsday-like forecasts plague efforts to assist disenfranchised people with autism spectrum disorder (ASD), a condition that has since skyrocketed in prevalence [5-7]. Though regulations to assist those with ASD have moved to the forefront of state and federal policy discussions, ASD initiatives compete with other pressing health care spending concerns to gain access to a finite amount of governmental resources. Satisfying the demand for high-quality, cost-effective ASD care requires well-researched, well-defined state and federal spending parameters that emphasize long-term patient outcomes as well as sustainable net gains.

In light of a growing national awareness about ASD in children, the latest regulations from the Centers for Medicare and Medicaid Services (CMS) have added applied behavior analysis (ABA) to the list of treatment modalities covered by Medicaid for those under age 21 [8]. Now, physicians and health care professionals in all states can code ABA as federally mandated early and periodic screening, diagnostic, and treatment services (EPSDT) [8, 9]. Many state legislatures have enacted autism-specific insurance mandates that require for-profit, commercial, health maintenance organization (HMO), and nonprofit health insurance companies regulated by the state to pay for medically necessary and evidence-based autism treatments for certain groups of people [10-37]. Of course, some state laws set forth more comprehensive and clearly defined eligibility and coverage criteria than others. Most state mandates require coverage until the patient reaches a certain age, usually in the range of 19 through 22 years [10-38].

Some forward-thinking policymakers are taking reform one step further by enacting groundbreaking ASD-specific Medicaid programs that not only expand the scope of services available to Medicaid beneficiaries with ASD, but also offer services like respite care and limited reimbursements to family member caretakers [8, 39]. New federal laws

create financial incentives for direct care by the family members of those with ASD by encouraging states to provide services to benefit the caregivers [8, 39]. Until recently, the notion of third parties—people other than the patient—receiving dollars from a patient's private or governmental insurance program was a rarity. During the last decade, the most common form of spending on third-party welfare was generally for mental health and grief counseling for the immediate family members of hospice patients [40-44]. This coverage of education, counseling, and medical social services acknowledges that one family member's health concerns can impact the well-being of the rest of the family [40].

The practice of valuing family members as part of a patient's unit of care can be applied to long-term care for ASD. After all, family member caretakers are, oftentimes, responsible for the day-to-day care of patients with ASD. For the good of families, patients, and the country's fiscal situation, we must continue to encourage family member involvement in caring for people with ASD, promote home or community-based care and, as appropriate, reduce reliance on overburdened Medicaid state plan and waiver programs. Since family members are often primary caregivers for people with ASD (particularly young children), it follows that, when a family caregiver's mental or physical health declines, patient outcomes can suffer. Maintaining a focus on clearly defined reimbursements, ASD-specific education, training, and other meaningful benefits for family member caregivers can increase families' direct involvement in ASD-specific care and, in turn, improve patient outcomes. Moreover, it can lower overall health care costs and help state and federal policymakers to balance competing budget expenditure priorities in the long term.

### **Economic Challenges Affecting ASD Reform**

To gain a more comprehensive view of the overarching economic impact of ASD, we must first acknowledge that the dynamics of ASD-related actions and omissions in health care reform cannot reasonably be considered in an economic vacuum. The predominant hurdle facing policymakers who wish to implement ASD insurance reforms is a dearth of overall resources. The country's fiscal situation is straitened primarily by three factors: (1) health care spending disproportional to the economy's annual output, or gross domestic product (GDP); (2) rapid growth in the population of elderly people (which drives up health care spending, particularly for long-term care of those covered by Medicare and Medicaid); and (3) large state and federal budget deficits. The Congressional Budget Office (CBO) identifies health care spending growth as one of the core fiscal challenges facing our government [45]. If current trends hold, by 2050 government health care spending will claim one-third of the GDP [46]. The US Census Bureau estimates that, in the not-too-distant future, the number of elderly people in the US will be twice what it is now [47]. If current government spending practices remain essentially unchanged, the federal debt held by the public will exceed 100 percent of the GDP in just 25 years [46]. According to government researchers, the federal government

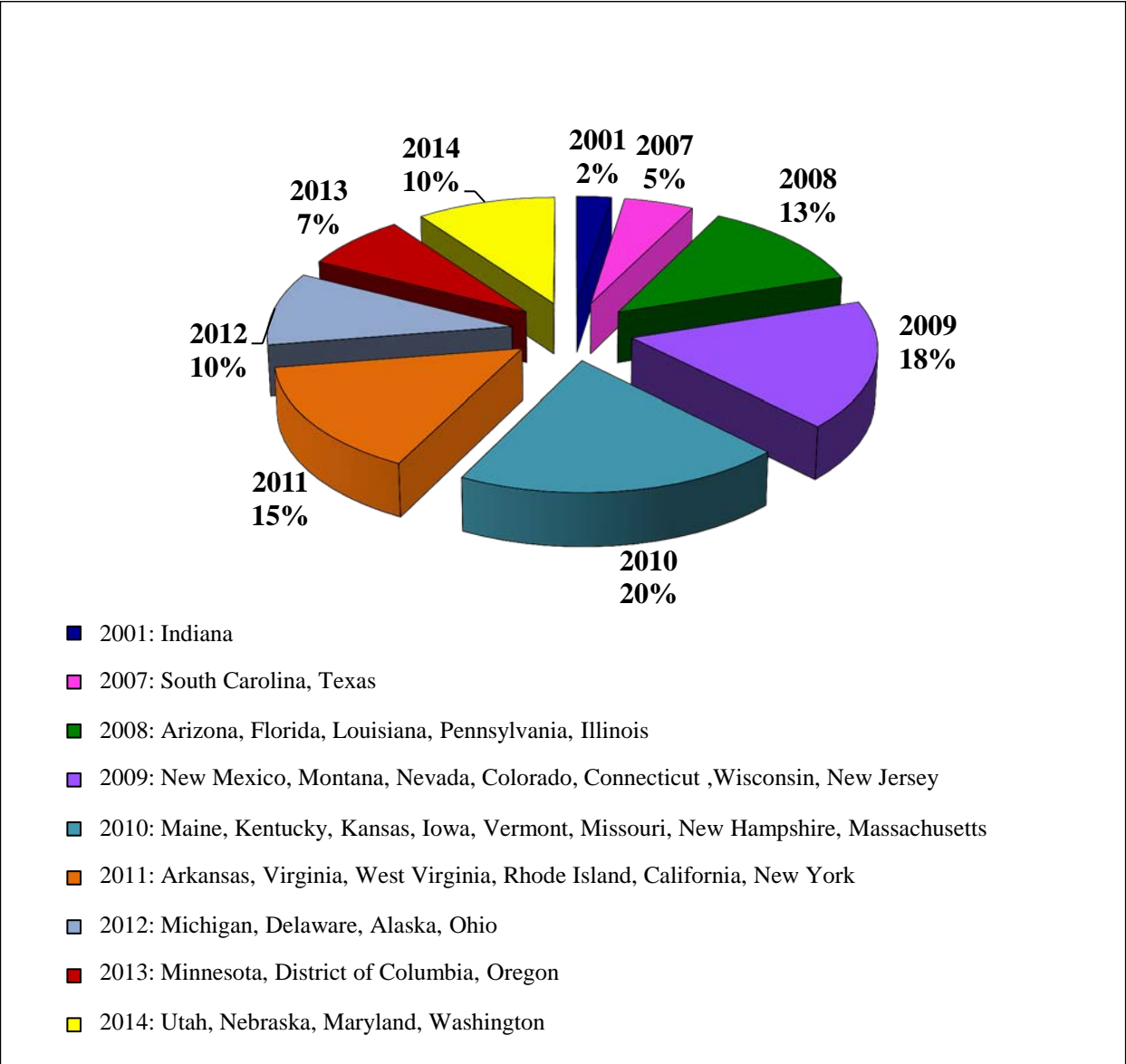
will have to ultimately raise taxes, cut spending for benefits and services, or both to create sustainable, long-term financing plans [48]. Some might argue that the scarcity of resources for ASD-specific reforms, on its face, suggests a solution that solely reduces services and coverage. Yet specific, pinpointed spending devoted to early intervention and support for caregivers today will, in fact, lower costs in the long run. We can empower patients and their families to improve and maintain their health now so these same people do not require far more costly health care services later in life.

### **Increasing Insurance Coverage through Governmental Mandates**

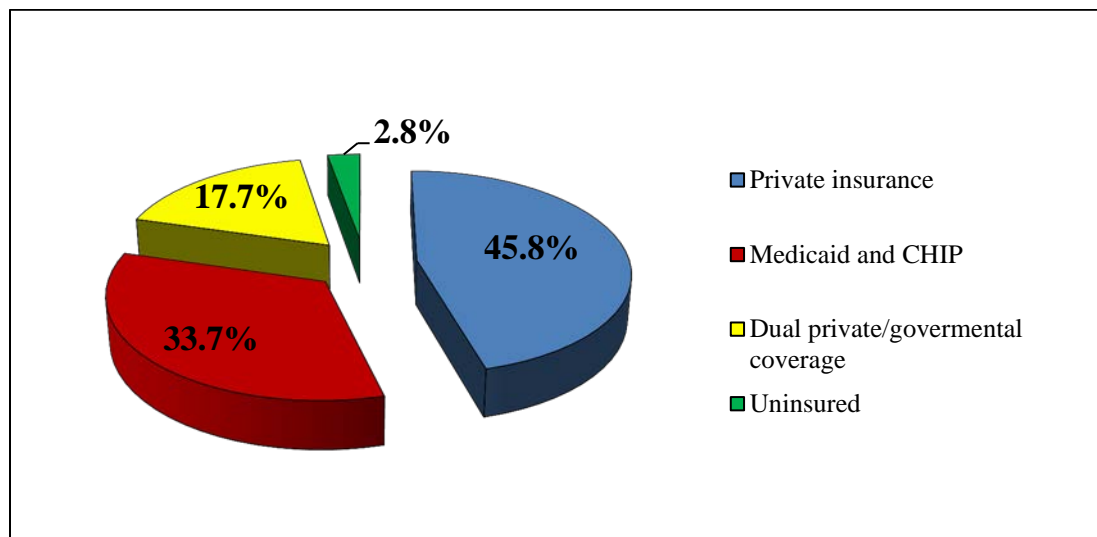
ASD insurance reforms often impact the scope of services required for all health insurance plan types available to people with ASD. These include government-subsidized plans in the state marketplace exchanges, the Children's Health Insurance Program (CHIP), Medicaid, private health insurance, and self-funded programs. Since 2001, ASD insurance reform laws have been enacted either by legislation or administrative mandates in 39 states and the District of Columbia (see figure 1) [49-51]. These laws provide varying degrees of services to people with ASD and are often limited by age classifications and "maximum benefit amounts" (annual payment limits for covered services). Nearly half of children and youth with ASD have private health insurance coverage [52], one-third of all children and youth with ASD are covered by Medicaid and CHIP, and 17.7 percent are dual enrollees in governmental and private health insurance (see figure 2) [52]. Eighty-six percent of Americans live in a state with some ASD reform statutes or administrative regulations, but more than 54 million people live in states without explicit ASD-specific state laws that clarify the breadth, length, and eligibility details for coverage beyond the federally mandated baselines for ASD care (see figure 3) [52, 53].

Under the Individuals with Disabilities Education Act (IDEA), states must provide early ASD intervention treatment to certain children under age three even if they do not have a formal ASD diagnosis [54]. Children must be deemed "at risk" for developmental delays to be eligible for these services [55]. Recognizing that those with ASD are likely to respond best to medical interventions performed while they are young, ASD reform advocates have long balked at health insurance providers' annual caps on the number of covered office visits [55]. Once patients exhaust the limited number of yearly treatments or office visits covered by their carriers, they and their families are often forced to rely on counselors and special needs programs within their state's public school system for ongoing ASD-specific care. In an effort to provide more progressive and effective ASD care, some states have eliminated annual caps and included a catchall provision in their statutes requiring that patients with ASD receive all medically necessary and evidence-based care as determined by a licensed physician [10, 14, 31, 34-38, 56-60]. To date, only Delaware and Arkansas specifically list medical equipment as a covered item for patients with ASD [10, 56]. While certain state laws expand covered mental health care beyond that received from psychiatrists and psychologists, only a few include specific

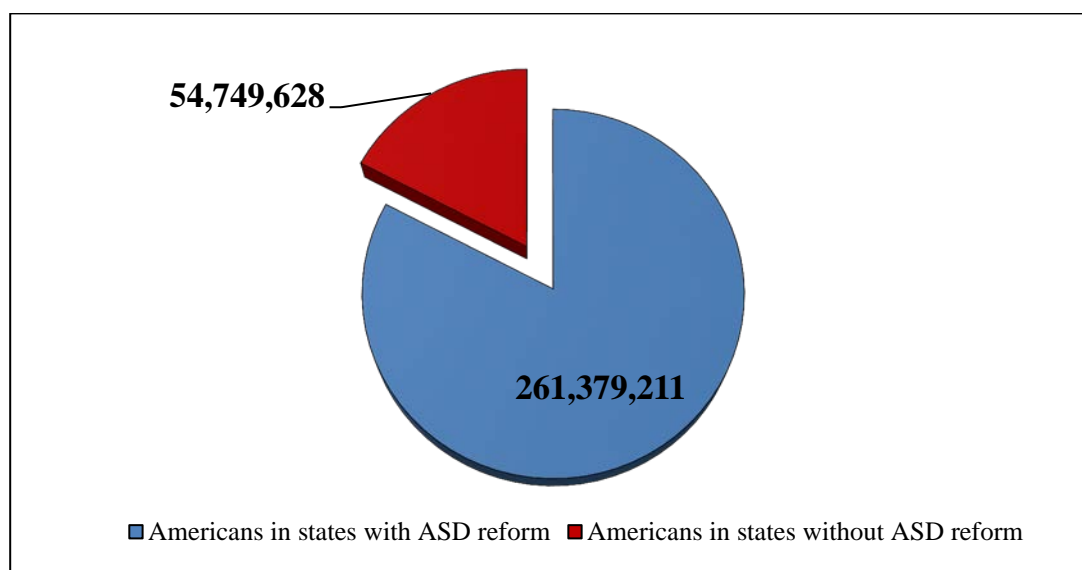
mention of which services from other specialists like certified nurse practitioners or clinical social workers are covered [14, 59, 60].



**Figure 1.** Enactments of state autism laws by year (2001-2014). Data includes ASD reforms enacted either by statute or administrative mandate [49-51].



**Figure 2.** Health insurance coverage for children and youth with ASH and other special health care needs [52].



**Figure 3.** Autism insurance reform and the US population. “ASD reform” includes any ASD-specific insurance reform law that has been enacted either by legislation or administrative mandate in 39 states and the District of Columbia [52, 53].

### ASD Care for Medicaid-Eligible Patients

Enacted in 1965, Medicaid offers government funding to help eligible populations with limited resources receive medical care [61, 62]. Covered demographics include people with disabilities who qualify for the Supplemental Security Income (SSI) program [63, 64]. Someone seeking Medicaid coverage of ASD-related services must meet certain income requirements and be registered as a person with a Social Security

Administration-classified disability [64]. Medicaid eligibility rules and covered services vary from state to state because, though eligibility and the scope of services covered are based on federal requirements, federal law grants states considerable leeway to decide how best to operate their programs. States can elect to expand health care services and coverage beyond the federally set minimum requirements. Medicaid includes long-term care services provided at home, such as visiting nurses and assistance with the activities of daily living [65]. Unlike Medicare, Medicaid is more likely to pay for custodial care at home or in a skilled nursing facility [65].

In July 2014, autism advocates won a hard-fought battle to include applied behavior analysis (ABA) as a Medicaid-covered treatment option for those under age 21. CMS confirmed that all states must offer ABA as one of the treatment modalities for eligible people under Medicaid's comprehensive and preventative EPSDT provision [8]. This was a significant victory, since 51 percent of children or youth with ASD are covered by either Medicaid, CHIP, or a combination of private and public health insurance [52, 66].

The rub is that ASD patients under 21 and on Medicaid can only obtain ABA services after "medical necessity"—the scope of which can vary from provider to provider and state to state—is shown [67]. In September 2014, CMS clarified its earlier statements about ASD-specific coverage, stating that states are obligated to provide all "medically necessary services available for the treatment of ASD" to Medicaid beneficiaries from birth to age 21 [9]. Baseline federal considerations for satisfying EPSDT's requirement that states provide medically necessary services include: (1) assessing and identifying problems early; (2) checking children's health at periodic, age-appropriate intervals; (3) providing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems; (4) performing diagnostic tests to follow up when a risk is identified; and (5) treatment to control, correct, or reduce identified health problems [67]. To determine the required frequency for periodic screening of patients on Medicaid, clinicians must apply "reasonable standards of medical practice" for the particular patient [67].

### **Easing the Burden of Disability**

Medicaid programs can pay for home and community-based services (HCBS) for people with ASD through the state plan as well as through Medicaid waivers [68]. Historically, Medicaid reimbursement standards favored state programs that covered people with disabilities in institutions but not people with the same disabilities living at home [68]. This is sometimes referred to as Medicaid's "institutional bias" [69]. It remains a state's choice whether to expand HCBS coverage to patients up to age 21 using Medicaid waivers, which "waive" the general requirement that Medicaid services be provided in an institution and allow the recipient to receive comparable services in a home or community setting [68, 70, 71].

Thirty-two states currently offer ASD-specific Medicaid waivers (often called “1915(c)” waivers) [70-72]. Standard services include but are not limited to case management, homemaker or home health services, personal care, adult day health services, habilitation (to help a person learn, improve, or keep skills for daily living), and respite care. States can also propose other types of services that may assist in diverting and/or transitioning patients from institutional settings into their homes and communities [70]. As the National Council of Disabilities (NDC) explains, the evidence overwhelmingly suggests that “people with disabilities living in small family-scale settings that they control are more likely to experience positive personal outcomes” than people living in larger settings that they do not control [72]. According to the NDC and National Core Indicators (NCI) studies, people with disabilities who live with a biological family caregiver (or a host family) generally have better decision-making abilities, personal well-being, and satisfaction than those living in an agency setting [72, 73].

Although HCBS Medicaid waiver programs can offer much-needed assistance, they are rife with problems. Many of the states that offer them cap the number of people who can receive waivers, leading to long government waiting lists. Also, the Medicaid waivers generally cannot enable reimbursement of guardians, parents, or spouses of waiver recipients for providing service, although county waiver agencies may choose to reimburse those persons using other funding sources [74]. Due to tremendous waiting lists in most states, a patient is unlikely to get a Medicaid waiver during the period immediately following diagnosis, when medical interventions would be most effective.

The Supreme Court has acknowledged that the care of people with disabilities is the “special obligation” of government [75]. Despite this ruling, as indicated above, federal, state, and municipal governments are struggling to adequately address their populations’ ASD-related needs because of stretched state budgets, the exploding costs of health care, and increasing demands for health care services (particularly from the aging Baby Boomer generation and previously uninsured people who are now covered under the Affordable Care Act). Many people with ASD have difficulty obtaining adequate health insurance, and interventions offered through private clinicians and other out-of-pocket service providers can place an enormous financial burden on families.

So, in December 2014, Congress attempted to mitigate some of these concerns by passing the Achieving a Better Life Experience (ABLE) Act, which recognizes that living with a disability is often associated with added costs [76]. Congress amended the federal tax code to allow people with disabilities (with an age of onset up to 26 years old) and their families to create tax-exempt savings accounts modeled on tax-free college savings accounts [76]. The funds can be used for quality-of-life expenses other than health care, such as education, housing, transportation, employment training, community-based support services, assistive technology, and financial planning [76]. Because ABLE savings accounts are not considered legal assets, they encourage greater



financial independence for people with disabilities without affecting their eligibility for supplemental security income (SSI), Medicaid, or other critical public benefits.

### **Family Caregivers as Part of The Patient's Unit of Care**

In August 2014, Congress passed the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES), which focuses on autism education, early detection, and intervention and includes funding to "provide evidence-based interventions for children with autism spectrum disorder" [39]. Under the law, Congress is obligated to pay only for these activities "subject to the availability of appropriations" [39]. The statute allows the federal government to make assistance provisions conditional on the state's creation of a lead agency to coordinate ASD education, early detection, and intervention initiatives [39]. In addition, the statute specifically requires lead agencies to assist "family members, guardians, advocates, or authorized representatives" by providing "comprehensive culturally competent" information about state and local ASD services in the form of useful phone numbers, websites, or mailed literature [39]. Interestingly, the statute specifically mentions that available supports "may include respite care for caregivers of individuals with an autism spectrum disorder" [39].

Until recently, federal laws have carved out only a small number of instances in which government-sponsored health insurance must pay for services provided to a patient's family member. For instance, Medicaid will cover comprehensive bereavement services for families of hospice patients, including services in home and community-based settings [10, 11, 77]. CMS has confirmed that the government prioritizes meeting the physical, emotional, and spiritual needs of both the patient and the patient's family in an effort to minimize the "stress and problems that arise from the terminal illness [and] related conditions" [78]. Views are shifting to recognize family member caretakers as part of the patient's unit of care. Policymakers are expanding this line of thought to ASD in recognition that ASD diagnoses can affect an entire family, not just the patient.

To enable family members to better assist their loved ones with ASD and become part of the government's cost savings solution, states must prioritize caretaker education and training mechanisms to assist with patients' and families' physical, emotional, and spiritual needs. Common sense dictates that able family caregivers can help prevent health declines, which are both medically devastating and terribly expensive. Caring for patients with ASD and their caregivers not only improves the development and long-term health of the patients, but also decreases their institutionalization and stress-based health complications for family member caretakers. These actions will, in turn, decrease overall health care spending and reliance on government-sponsored programs.

## Conclusion

To encourage long-term savings on lifelong care for patients with ASD, state and federal policies must continue to prioritize early diagnosis and intervention spending now to avoid more costly services for diminished patient outcomes in the future. The Centers for Disease Control (CDC) state that the unwanted symptoms of ASD, particularly in their early stages, can be mitigated and the earlier a child can receive the proper treatment, the better [55]. Rationing medically necessary and evidence-based treatments when children are young (and most likely to benefit from intensive therapy) is a poor long-term strategy for managing health care costs. Laws that limit a child's access to health insurance coverage for ASD treatments now will engender substantially higher costs for care in the future. Costs will be substantially lowered when children with ASD can benefit from treatments and, as adults, function independently or semi-independently in a home or community setting.

Common sense further dictates that, if family members are brought into the fold of the patient care unit—educated, trained, and medically supported to avoid their own health declines—they can help to mitigate the need for more costly intensive therapies (including institutionalization) for their loved ones with ASD. The National Research Council states: "Education, both directly of children, and of parents...is currently *the* primary form of treatment for autistic spectrum disorders" (emphasis added) [79]. Without equivocation, dollars spent today to educate, support, and empower family member caregivers—those in the front lines of the fight to improve the well-being of people with ASD—will yield durable medical and economic benefits.

We can continue to build on this knowledge with meaningful ASD reforms at the federal, state, and country levels by focusing on four primary goals:

1. Utilizing statutory catch-all provisions to give physicians and health care professionals a wide berth to order all medically necessary services for ASD care, particularly for children and youth;
2. Ensuring the parameters of covered ASD services are clearly and specifically defined in our laws to help prevent gaps in necessary treatments;
3. Investing in teaching ASD-specific care skills for family member caregivers; and
4. Ensuring family member caregivers have the physical, emotional, and spiritual supports they need to provide ongoing care for their relatives with ASD.

Despite remarkable advances in medical science surrounding ASD, the amount of public money to devote to ASD care remains controversial [80]. Two fundamental and weighty questions persist: (1) where is government money best spent to accomplish this goal and (2) how much spending is necessary? To create fiscally responsible action plans that focus on achieving and maintaining sustainable, long-term results, we must construct meaningful data sets by melding evidence-based research from multiple disciplines including medicine, mental health, economics, accounting, sociology, policy, and law.

Until silos are broken down and professionals in many disciplines are willing to work together in ways they perhaps never have before, ASD will unduly challenge the lives of patients and those who love and care for them.

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**Annemarie M. Kelly, JD, LLM**, serves as counsel as in the Medicaid Third Party Liability Division of the Michigan Department of Community Health in Lansing. She has practiced on behalf of physicians and hospitals in Michigan, Illinois, and Iowa in medical malpractice and contract dispute cases. A staunch advocate for community health issues, Annemarie volunteers for multiple child health services organizations in the greater Chicago and Lansing areas. She received her JD from Drake University and her LLM fellowship degree in health law from the Loyola University Chicago School of Law.

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## POLICY FORUM

### **A Life of One's Own: Challenges in the Transition from Childhood to Adulthood with Autism Spectrum Disorder**

Kayhan Parsi, JD, PhD, and Nanette Elster, JD, MPH

This is a very delicate age for Cameron, with his eighteenth birthday looming like a big exit sign. Should I establish guardianship? Am I limiting his independence if I do? Am I putting him at risk if I don't? Will he be able to earn a meaningful living and be able to support himself? If not, are there supports available for him, aside from me? These questions weigh heavy on my mind, as time seems to speed up the older Cameron gets. I am encouraged by the pride Cameron shows in his independence, and hope that pride continues to grow, along with his independence [1].

Autism spectrum disorders (ASD) have become the focus of researchers, policymakers, and, most of all, the parents of children who are diagnosed with ASD. For years, children have merited the lion's share of attention to people with ASD. This is not surprising. Children in general are vulnerable members of the community and merit special protection. Moreover, children with ASD figure prominently in the broader culture. Witness the popularity of autism memoirs by parents of children with ASD (e.g., *Life, Animated*) or the success of television shows such as *Parenthood* that feature a child character with Asperger syndrome. We are only now, however, beginning to recognize that children with autism will eventually become adults with autism. What are the unique social, ethical, and legal, challenges that this transition poses? In this essay we will examine this set of challenges.

#### **What the Transition to Adult Health Care Entails**

As Hendricks and Wehman have observed, although the transition from childhood to adulthood can be an exciting one for many neurotypical young people as they venture forth seeking new experiences and adventures, it can be a particularly challenging time for young people with ASD [2]. First of all, there are significant differences in the services available to children with autism and those available to adults with autism. Children are entitled to a range of educational, health care, and social services. Public schools are required by federal law to provide free and appropriate education to children with special needs [3]. And many states have laws that mandate some level of insurance coverage for services for children with ASD [4]. The Department of Health and Human Services has compiled a list of some of the services that are available for children with ASD, including descriptions of what is available under the Affordable Care Act (ACA) and the



Combating Autism Act [5, 6]. Adults with ASD, however, are merely *eligible* for housing, health care, and employment. Eligibility rather than entitlement requires that the individual or his or her guardian first be aware of the potential services available and then understand and initiate the process of determining eligibility. The most significant distinction, however, is that eligibility, unlike the entitlements children with ASD have, does not guarantee access to or acceptance in a program for services.

Another key distinction is that parents or guardians are the legal decision makers for children. As the case of Cameron illustrates, unless parents petition for guardianship of their adult children with ASD, an adult with ASD can legally make a number of decisions for himself or herself (including accepting or refusing health care).

Lastly, pediatric health care centers on the child's holistic health needs, but health care for adults with ASD is less integrated; there is little focus on identifying and maintaining a medical home for them and on training internists on how to facilitate the transition. According to a 2010 survey by Patel and O'Hare, "most IMRs [internal medicine residents] had received little or no formal training for how to transition these [ASD] patients" [7].

### **HCT Education and Less Costly Solutions Are Needed**

The need for improved health care transition (HCT) among this population of young people is critical. Less than a quarter of youth with ASD receive appropriate services [8]. This figure is even lower than that for the broader population of youth with special health care needs (YSHCN), suggesting that disparities exist not only between young people with ASD and the general population but also between youth with ASD and those with other special needs [8].

The health care disparities between youth with ASD and both typical youth and YSHCN are striking. In general, young adults have benefited from certain policy innovations, such as the Affordable Care Act (ACA), which allows young adults under 26 to remain on their parents' health insurance. Although this option provides health care coverage well into adulthood, questions loom not only about what will happen after that point, but about whether the care being provided under parents' policies meets the needs of an adult with ASD.

Parents' involvement in the health care transition is essential. Many young adults with ASD still depend upon their parents to identify and provide, directly or through financial means, housing, health care, and postsecondary training or education. And having an educated parent—normally a predictor of greater use of social services—does not necessarily translate into greater use of HCT services for young adults with ASD. Surprisingly, Cheak-Zamora et al. discovered that better educated mothers of young adults with ASD actually "reported lower rates of HCT services than those with less

education” [8]. Thus parents need to be better educated about what HCT services are available in their communities and how to get access to them.

Education and training is also needed for health care professionals working with this population. In a recent study, Kuhlthau et al. cited one respondent who highlighted this need:

I think it would be a really good idea if some curriculum towards family practice training [was developed for]—residents in family practice or—and probably undergraduates in medical school as well. I think there needs to be more in the curriculum about autism and other developmental disabilities [9].

The need for educating and training health care professionals in HCT for patients with ASD has been endorsed by a number of professional organizations and societies. Well over a decade ago, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians coauthored a joint report on supporting HCT for youth with special care needs, particularly citing the need for greater training [10]. The Maternal and Child Health Bureau in the US Department of Health and Human Services issued a similar report on the services needed for this group of young people [11]. Cheak-Zamora and colleagues are hopeful that the ACA will provide funding to train more health care professionals to address the particular needs of this population of young people [8].

Even if parents and health professionals are educated in HCT, continued financial reliance on parents of adults with ASD may lead to a more complicated and costly solution in the long run. Parents will age. Their own health care needs will increase. They may be on fixed incomes. If, as a society, we rely on parents to meet the needs of their adult children with ASD, considerable financial burdens will extend beyond the parents to the broader society. As Ganz observes:

the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs...have important implications for those aging members of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general [12].

Ganz recommends financial counseling for parents of young adults with autism as they go through this critical transition time.

Increasing employment and other opportunities for young adults with ASD can also help alleviate this financial burden. Employers are seeking to recruit young adults with ASD [13], and more programs are available to equip these young adults with necessary work skills [14]. There should be more integrated care that addresses not just health and employment but also services to help these young adults maximize their potential. Such services may include continued applied behavioral analysis therapy, occupational therapy, physical therapy, and speech therapy.

### **Ethical and Legal Issues in Facilitating HCT for Patients with ASD**

*Capacity and health care decision making.* Physicians treating young adults with ASD confront fundamental ethical questions. For instance, do traditional ethical rules of patient autonomy apply to caring for a young adult with ASD? Can a physician employ soft paternalism with such a patient if the physician believes that the patient is electing to do something contrary to his or her best interest? Again, many young adults with ASD may need a guardian to help make health care decisions and to assist with the financial aspect of accessing health care. But what happens to those who lack a guardian because they are higher functioning or because a parent or family member is unavailable or unwilling to accept the role of decision maker? Should physicians scrutinize their patients' decision making even more closely because of their ASD? In short, does a diagnosis of ASD presume a lack of capacity?

Although a diagnosis of ASD does not preclude decision-making capacity, young adults with ASD, like other patients, may have capacity that waxes and wanes. Primary care physicians treating young adults with ASD should take greater care to include parents when needed. The medical history should have a robust and detailed account of the patient's psychosocial and family history. Learning about the patient's unique health and social challenges is imperative.

*Employment.* Whether patients are employed is typically seen as beyond the purview of health care professionals. But if we take a broader biopsychosocial approach to care (or even a public health approach), we must recognize the relationship between employment and overall health. The sense of independence that employment brings is a powerful social determinant of health, not just for neurotypical individuals but for the many young adults who have ASD. As the opening quote from Cameron's mother suggests, some level of independence is what all parents of young adults with ASD want for their sons and daughters. Ensuring that these young people are equipped with the appropriate skills to secure and maintain employment is yet another significant milestone in the larger transition from childhood to adulthood.

In sum, we believe the barriers to HCT can be overcome with greater education, communication, and access to and availability of resources. The current generation and future generations of young adults with ASD depend upon it.

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**Kayhan Parsi, JD, PhD**, is a professor and the director of graduate studies in the Neiswanger Institute for Bioethics and Health Policy at Loyola University Chicago Stritch School of Medicine. His research interests are in clinical ethics, ethics education, global health, and professionalism and professional ethics.

**Nanette Elster, JD, MPH**, is a lecturer in the Neiswanger Institute for Bioethics and Health Policy at Loyola University Chicago Stritch School of Medicine. She has extensive experience in legal, public health, and ethical issues related to women's and children's health.

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## MEDICINE AND SOCIETY

### The Myth of the Normal Brain: Embracing Neurodiversity

Thomas Armstrong, PhD

In the basement of the Bureau International des Poids et Mesures (BIPM) headquarters in Sevres, France, a suburb of Paris, there lies a piece of metal that has been secured since 1889 in an environmentally controlled chamber under three bell jars. It represents the world standard for the kilogram, and all other kilo measurements around the world must be compared and calibrated to this one prototype. There is no such standard for the human brain. Search as you might, there is no brain that has been pickled in a jar in the basement of the Smithsonian Museum or the National Institute of Health or elsewhere in the world that represents the standard to which all other human brains must be compared. Given that this is the case, how do we decide whether any individual human brain or mind is abnormal or normal? To be sure, psychiatrists have their diagnostic manuals. But when it comes to mental disorders, including autism, dyslexia, attention deficit hyperactivity disorder, intellectual disabilities, and even emotional and behavioral disorders, there appears to be substantial uncertainty concerning when a neurologically based human behavior crosses the critical threshold from normal human variation to pathology.

A major cause of this ambiguity is the emergence over the past two decades of studies suggesting that many disorders of the brain or mind bring with them strengths as well as weaknesses. People diagnosed with autism spectrum disorder (ASD), for example, appear to have strengths related to working with systems (e.g., computer languages, mathematical systems, machines) and in experiments are better than control subjects at identifying tiny details in complex patterns [1]. They also score significantly higher on the nonverbal Raven's Matrices intelligence test than on the verbal Wechsler Scales [2]. A practical outcome of this new recognition of ASD-related strengths is that technology companies have been aggressively recruiting people with ASD for occupations that involve systemizing tasks such as writing computer manuals, managing databases, and searching for bugs in computer code [3].

Valued traits have also been identified in people with other mental disorders. People with dyslexia have been found to possess global visual-spatial abilities, including the capacity to identify "impossible objects" (of the kind popularized by M. C. Escher) [4], process low-definition or blurred visual scenes [5], and perceive peripheral or diffused visual information more quickly and efficiently than participants without dyslexia [6]. Such visual-spatial gifts may be advantageous in jobs requiring three-dimensional

thinking such as astrophysics, molecular biology, genetics, engineering, and computer graphics [7, 8]. In the field of intellectual disabilities, studies have noted heightened musical abilities in people with Williams syndrome, the warmth and friendliness of individuals with Down syndrome, and the nurturing behaviors of persons with Prader-Willi syndrome [9, 10]. Finally, researchers have observed that subjects with attention deficit hyperactivity disorder (ADHD) and bipolar disorder display greater levels of novelty-seeking and creativity than matched controls [11-13].

Such strengths may suggest an evolutionary explanation for why these disorders are still in the gene pool. A growing number of scientists are suggesting that psychopathologies may have conferred specific evolutionary advantages in the past as well as in the present [14]. The systemizing abilities of individuals with autism spectrum disorder might have been highly adaptive for the survival of prehistoric humans. As autism activist Temple Grandin, who herself has autism, surmised: "Some guy with high-functioning Asperger's developed the first stone spear; it wasn't developed by the social ones yakking around the campfire" [15].

Similarly, the three-dimensional thinking seen in some people with dyslexia may have been highly adaptive in preliterate cultures for designing tools, plotting out hunting routes, and constructing shelters, and would not have been regarded as a barrier to learning [16]. The key symptoms of ADHD, including hyperactivity, distractibility, and impulsivity, would have been adaptive traits in hunting and gathering societies in which people who were peripatetic in their search for food, quick in their response to environmental stimuli, and deft in moving toward or away from potential prey would have thrived [17]. There might also have been evolutionary advantages in prehistoric times for people with mania, since high energy and creative expression might have fueled sexual and reproductive success [18].

The cumulative effect of these studies suggests that a more judicious approach to treating mental disorders would be to replace a "disability" or "illness" paradigm with a "diversity" perspective that takes into account both strengths and weaknesses and the idea that variation can be positive in and of itself. To this end, a new term has arisen within the autism rights community: neurodiversity. Although the origin of the neurodiversity movement is often traced back to a speech entitled "Don't Mourn for Us," given by autism activist Jim Sinclair at the 1993 International Conference on Autism in Toronto [19], the word itself was first used by autism rights advocate Judy Singer and New York journalist Harvey Blume to articulate the needs of people with autism who did not want to be defined by a disability label but wished to be seen instead as neurologically different [20, 21]. Since that time, the use of the term has continued to grow beyond the autism rights movement to fields such as disability studies, special education, higher education, business, counseling, and medicine [22-27]. Embracing the concept of neurodiversity would bring the study of mental health disorders in line with

movements that have already taken place over the past 50 years around biodiversity and cultural diversity [28, 29]. As Harvey Blume noted, “Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment?” How absurd it would be to label a calla lily as having “petal deficit disorder” or to diagnose a person from Holland as suffering from “altitude deprivation syndrome.” There is no normal flower or culture. Similarly, we ought to accept the fact that there is no normal brain or mind.

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**Thomas Armstrong, PhD**, is the executive director of the American Institute for Learning and Human Development in Cloverdale, California. He is the author of 15 books, including *The Power of Neurodiversity: Unleashing the Advantages of Your Differently Wired Brain* (Da Capo Press, 2011) and *Neurodiversity in the Classroom: Strength-Based Strategies to Help Students with Special Needs Succeed in School and Life* (ASCD, 2012). His books have been translated into 26 languages, and he has lectured on learning and human development themes in 44 states and 25 countries over the past 29 years.

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## HISTORY OF MEDICINE

### Mothers and Autism: The Evolution of a Discourse of Blame

Mitzi M. Waltz, PhD

“Study says cost of autism more than cancer, strokes or heart disease” [1]. This was one of many “screamer” headlines announcing new research on the cost to the UK and US economies of lifespan care for people with autism spectrum conditions [2]. Lost in media examinations [3, 4] of these 2014 cost estimates—which can be misleading, since only a small minority of people with autism ever receive the “ideal” services on which the cost estimates were based—was that they were predicated on the assumption that mothers of children with autism work less and purchase large packages of services, many of which are not supported by evidence and may be more costly than services shown to be effective.

This is one topic around which autism’s past intersects with its present. The current expectation of full-time, “professional” autism parenting is rooted in a discourse of mother blaming persistently woven into the history of autism, even before the condition was named and defined.

This history begins with a moral panic over the behavior of the urban poor. A new notion of middle-class childhood that arose at the end of the nineteenth century, characterized by pampering, protection, and education, fostered fears over “troublesome” children: children with disabilities or low intellectual ability, street children, and juvenile delinquents. Children in these categories were targeted by a child-saving movement funded by the upper class and staffed by the middle class, particularly middle-class women. United in their vision that poverty, immorality, and antisocial behavior could best be attacked by reshaping childhood, these “child savers” undertook myriad initiatives: compulsory education, settlement houses, juvenile courts, reform schools, welfare departments, child protection organizations, and research centers focused on child psychology, psychiatry, behavior, and criminology [5, 6].

The child-saving institutions most relevant to later treatment of autism were child research facilities and the Child Guidance movement, which sought to put research findings into practice. In 1922 the Commonwealth Fund boosted the campaign to prevent delinquency by underwriting demonstration programs at American Child Guidance clinics for children with emotional and behavior problems as well as those believed to have criminal tendencies, and by spreading the use of standardized

psychological and intelligence testing [7]. For the first time, the mass population of children and mothers could be examined.

Clinical work was typically with mothers rather than the children themselves. For example, sociologist Ernest Groves, who with his wife Gladys Groves pioneered marriage counseling within Child Guidance clinics, declared that even typical mothering was pathological and in need of scientific improvement. The Groveses suggested that both too much affection and too little attention could impair development and directed parents towards professional guidance to get the balance right [8]. Through books, radio programs, speaking tours, and magazine articles, pundits like the Groveses, pediatrician and psychoanalyst D.W. Winnicott, and, eventually, psychologist Bruno Bettelheim sought to change the behavior of mothers to prevent social disorder, crime, and disability. Only with professional guidance and scientific practice, they argued, could mothers save their children and, by extension, society. "Correct" mothering practice was extensively described, starting with the right way to hold and feed an infant and moving on through when and how often children should be hugged, kissed, scolded, or spanked. Psychologists claimed correct maternal behavior would lead to hard-working, self-disciplined, law-abiding adults; any variance would create weak-minded, badly behaved, aberrant adults with a propensity for crime and radicalism [9].

In this context, under the direction of psychiatrist Adolf Meyer at Johns Hopkins University, Leo Kanner established in 1930 the first US child psychiatry clinic [10], which was strongly influenced by Child Guidance precepts [11]. Meyer introduced two key principles: the primacy of the case study in child psychiatry research and mother blaming. Meyer wrote that the home studies he performed with his wife, Mary Potter Meyer, "obtained help in a broader social understanding of our problem and a reaching out to the sources of sickness, the family and the community"—that is, to mothers [7].

Kanner's small collection of case studies defined what he called "autism" as a unique psychiatric disorder starting in childhood. Although his highly influential first article points to possible "inborn" causes [12], his assumptions about parental causation are clear throughout his first article (the case studies include long, negative descriptions of the children's parents) and many subsequent writings [13]. Nor was Kanner alone in his beliefs: other influential theorists, such as Margaret Mahler, Melanie Klein, and Frances Tustin also identified aberrant parenting as the cause of autism [9]. As schizophrenia, too, was assumed to have a parental cause—the "schizophrenogenic mother" [14]—the borrowing of the term "autism" from Eugen Bleuler's early writings about schizophrenia and the decades-long use of "childhood schizophrenia" as a synonym for autism further cemented this concept.

Along with their now-much-maligned colleague Bruno Bettelheim, who further popularized the figure of the "refrigerator mother," these eminent researchers were

wrong [15, 16]. Parents needed only to look at their other, nonautistic, children to see it. But challenging a hegemonic discourse is difficult, and it was especially so in this context, since the Child Guidance movement had long since popularized the idea that professionals were far more knowledgeable and trustworthy than ordinary parents.

In response, however, starting in the 1960s, parents created support and pressure groups. Better research, often driven by parent-researchers like Lorna Wing, slowly turned the tide away from the idea that mothers' behavior caused autism. Change was nonetheless slow: as late as 1983, researchers still felt the need to point out the poor evidence base linking parental pathology and autism and to reexamine the literature about it [15]. Experts have since reached a general consensus on this topic [16]. But rather than disappearing, mother blaming adopted more covert guises.

Behaviorist methods for treatment of autism, first popularized in the 1970s by Ivar Lovaas, were also predicated on mother blaming. Many radical behaviorists saw infants as a "blank slate" onto which behavior was imprinted through infant-parent interactions [17]. Lovaas's applied behavior analysis (ABA) therapy presented methods for teaching absolute obedience to adult demands and behavioral conformity as a "treatment" for autism, the stated goal of which was to make children with autism "indistinguishable from their peers" [18]. This was to be achieved through up to 40 hours per week of repetitive drills, typically carried out by mothers working one-to-one with their child under professional supervision. ABA is still considered a mainstream approach, despite ethical concerns, high costs, and an uneven track record [19]. Such intensity demands that mothers be engaged in "therapeutic parenting" almost every waking moment. This is only a subtler iteration of the child-saving mentality that places blame for autism, via responsibility for prevention or amelioration, on mothers' heads.

No longer the abjected "refrigerator mother," today's "autism mom" is supposed to be a child-saving hero, expected and encouraged to do anything and everything in pursuit of normalcy, from special diets to special schools, from medications to therapeutic toys. The discourse, however, remains one of covert parental guilt: if your child becomes an autistic adult, it's your fault because you failed to do enough to save him or her. The autism mom must position herself as a heroine, locating and tirelessly attacking the threat of autistic symptoms through purchase of the right therapies; avoiding "toxins" in the diet, environment, and medicines; and accepting that autistic behavior is wrong and must be countered via psychiatric medication or direct action. Although it is tiring, expensive, and frustrating, many parents feel driven to take up this role: it was parents who founded and funded most of the earliest autism-specific schools and therapy programs in the 1960s and 1970s [20]; it is also largely parents who have led the recent autism-focused crusade against vaccinations.

This social pressure to save one's child together with socioeconomic changes in the neoliberal state, in which public services are defunded and increasingly unavailable, have resulted in direct marketing to the medicalized family home. The most dangerous, bogus therapies, from Lupron injections to bleach enemas, have been promulgated through direct appeals to mothers. The memory of direct mother blaming persists, emerging as a distrust of traditional medical and educational experts. Parents are expected by the state to act as treatment coordinators and valorized by other parents for taking the most visible, costly, and extreme steps, as if by doing so they can ward off blame.

Those selling interventions for autism have since the 1960s used parents as marketers and sometimes as shields against criticism. For example, the since-discredited drug Secretin was marketed via parent testimonials, first on Internet mailing lists and then on national television [21]; today dodgy stem cell clinics routinely rely on "parent testimonials" on mailing lists or social networking sites to bring business their way [22]. In France, where psychological explanations continue to hold sway, parent advocacy groups have become the marketing agents for "modern" therapies like ABA that appear to shift blame away from parents [23]. Parents have been marshalled to defend the indefensible, including abusive programs—for instance, by being encouraged to write letters to newspapers and judges praising facilities where autistic children have been harmed or having their stories disseminated as a cover for discredited practitioners like Andrew Wakefield [9].

And yet, despite intense parental effort, children with autism continue to become adults with autism. Services shown by research to have measurable impact on outcomes are few, although special education, not generally available before the 1970s, can help [24].

The costs of continued mother blaming are high, and not only financially. Encouragement to heroics can cause direct physical harm to autistic people. Psychological damage may also occur, both to wrongfully guilt-ridden parents and to people with autism, who get the message that they are "sick" or even, since some extreme therapies carry fatal risks, that having autism is a fate worse than death. The extreme focus on child saving also contributes to a lack of services for autistic adults: if you believe your child can and should be cured, that becomes the goal rather than fighting for inclusion, services, and support in partnership with disabled adults. For the sake of people with autism and their families, we need to do better.

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**Mitzi M. Waltz, PhD**, is an associate lecturer in autism studies at the Autism Centre, Sheffield Hallam University, in Sheffield, UK, and a senior researcher for Disability Studies in Nederland in Amersfoort and at Rotterdam University of Applied Sciences in The Netherlands. Her interests are in the history of autism, media and clinical representations of disability, and improving life outcomes for people with autism and their families.

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# AMA Journal of Ethics

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## IMAGES OF HEALING AND LEARNING

### *Drawing Autism: Showcasing the Artistic Talents of People with Autism*

Jill Mullin, MA, MEd

Over the past 15 years I have worked as a board-certified behavior analyst with many talented people on the autism spectrum. Some have been excellent at memorizing patterns, such as license plate numbers; others have excelled at math from a very young age. Individuals on the spectrum have long been recognized to have the potential to be very talented, although these talents were often assumed to be restricted to math and science, with an emphasis on memorizing information. *Drawing Autism* [1], a collection of images and artwork by individuals on the ASD spectrum, illustrates that the potential for talent of people with ASD stretches far beyond math and memory. More than 40 international artists, all diagnosed with autism, are featured in *Drawing Autism*. The artwork demonstrates a staggering array of talent and style, as well as an insight into some of the characteristics of autism.

The impetus for *Drawing Autism* began with an artist I worked with at a residential facility in New York City. Glen, a young man with autism, loved to draw his favorite bands, as he knew them from seeing them on television shows. Not only did he enjoy drawing these figures (he would draw about 30 to 50 each week), but he had a great talent for making caricatures. His stick figures had an expressive, fun-loving nature.

Glen has difficulty interacting socially and communicating, especially when he is frustrated. Drawing is a great leisure activity for him. It is a hobby that he can enjoy each day after returning home from his daytime program. It gives him the freedom to create what he wants to create. His art also serves as a way for him to connect with the staff at his group home.

When I first met Glen he had recently moved out of his family home and was making the transition to a new, group-living situation. Asking questions about his artwork was a great way for the staff to get to know Glen and ultimately find out about his interests. It let me to get to know Glen, too, and helped guide some of his therapy: increasing leisure activities helped reduce problem behavior.

Getting to know Glen not only as an artist but also as a person sparked my interest in reading about and researching other artists with autism. I found some great artists but no cohesive collection of the amazing art created by people with ASD created. So *Drawing Autism* was born.

*Drawing Autism* has been a great journey. When the first edition was published, some of the artists were already successful in the art world, but many were just starting out, trying to build their careers, or had no aspiration to make art their career—it was just something they loved to do. In the years since the original edition was published, the artists have reported to me that they have had many opportunities. A few have been able to travel to museums and galleries that displayed their work, and others report that they have been successful selling their work, essentially launching careers as professional artists.

The paintings and drawings in *Drawing Autism* serve as a point of entry for understanding what it means to say that autism is a spectrum disorder. Some of the featured artists are higher-functioning, live independently, and have jobs and careers, and some are lower-functioning, nonverbal, in need of assistance with daily living skills, or unable to live on their own.

When I first started collecting submissions for the book, I began to recognize themes such as social isolation, repetitions and patterns, and an overwhelming interest in vehicles and history. I decided to group the artwork into chapters that represent commonalities within the artwork and among individuals with autism. What did not fit into a particular group was gathered in the chapter, “Art for Art’s Sake.”

Along with featuring their artwork, the contributors (or their parents or guardians) gave responses to the following set of questions: At what age did the act of creating art enter into your life? Why did you start creating art? What inspires/excites you about creating art? How do you choose your subjects? Why do you paint/draw what you do? Do you think your art helps others understand how you view the world? The most revealing answers accompany the artwork, providing insight into the pieces as well as the artists and, ultimately, autism.

In my work with those who have autism and their families, I have seen how art can be a positive experience not only for the artist but also for his or her family, endowing them with an invaluable sense of pride and satisfaction. The greatest gratification I’ve had since the book was first published has been meeting contributors and seeing just how much it means to them to be featured in this book. *Drawing Autism* is not a clinical book, but it sheds a vibrant light on autism and lets readers know just how important art can be.

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**Jill Mullin, MA, MEd**, is a board-certified behavior analyst and the regional coordinator for Applied Behavior Consultants, Inc., in Portland, Maine. She holds a master's degree in general and special education from Touro College and a master of arts degree in psychology with a concentration in applied behavior analysis from the University of the Pacific. She has worked closely with individuals diagnosed with autism and their families for 15 years.

**Related in the *AMA Journal of Ethics***

[Artwork by People with Autism](#), April 2015

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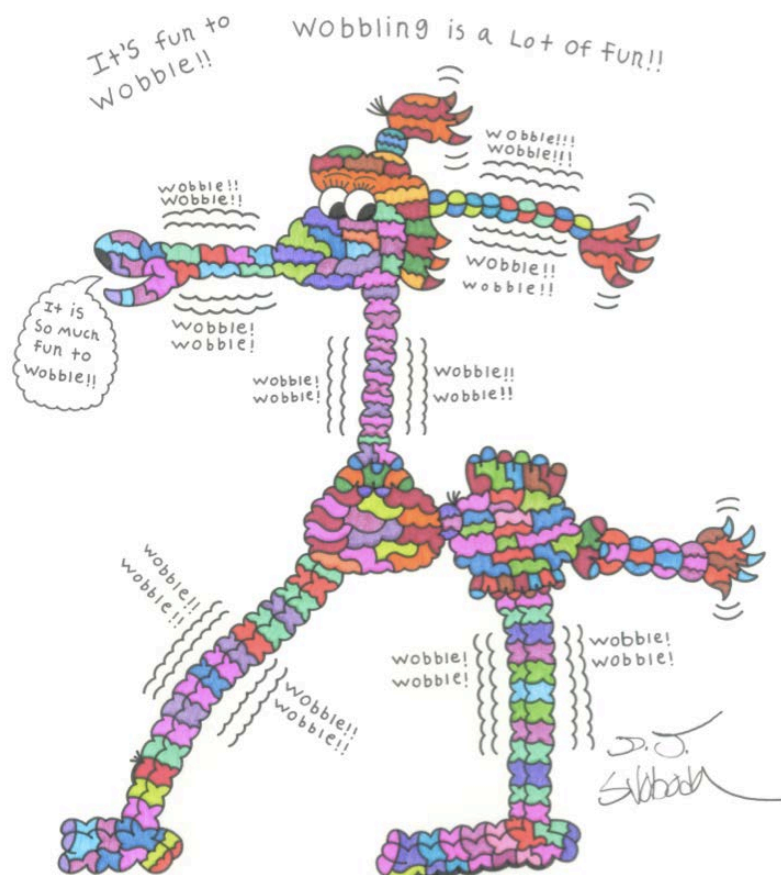
## IMAGES OF HEALING AND LEARNING

### Artwork by People with Autism

D.J. Svoboda, Kevin Hosseini, Noah Schneider, Emily Casanova, PhD, and Kay Aitch

#### D.J. Svoboda

My name is D.J. Svoboda, and I am an artist diagnosed with Autism. I am the creator of the Imagifriends of Imagiville. The Imagifriends of Imagiville are based on the experiences I have faced during times at school. There were days at school when I was made fun of, and when I was picked on and treated mean. Those made me feel very sad and hurt. That is how I got the idea of the Imagifriends of Imagiville.... Now I want to share my experiences to help open people's minds, hearts, and souls to have more compassion and awareness for Autism.

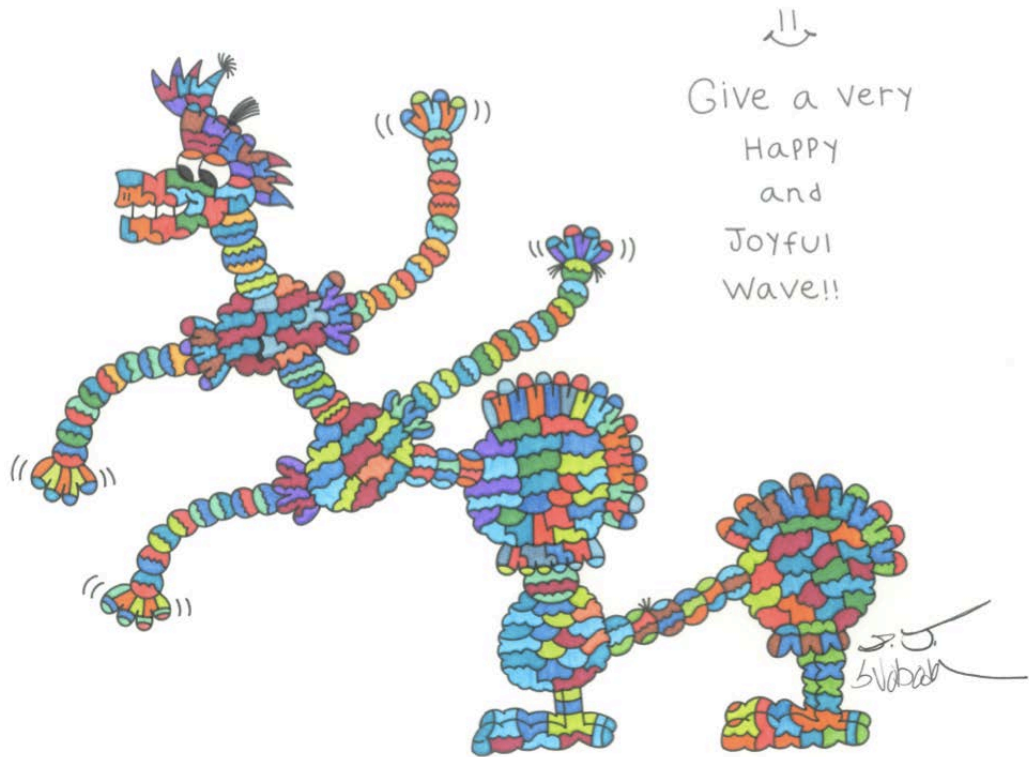


The Wobbling Saruvogoo

This is a Very Cheery Friend who always Loves to Wobble. No, it is not because she is Clumsy, No Way! It is because she is so full of Cheer and excitement that she always loves to Wobble for Fun and to show Her Cheer and Joy. When you see Her Wobbling you will also see that she is full of Great Joy and also Great Cheer!!

All those with Autism and Disabilities and Special Needs show and express their feelings in different ways.

When I am filled with Excitement and cheer I love to shake and Dance and even Wobble too.



### The Happy Waving Habfreedook

This is a Very Happy Friend who always loves to Smile and Wave Everywhere He goes. When He waves He loves to show Joy and Care and Kindness. He also Loves to Wave because it makes his Hands feel really good, But most of all he loves to Wave to everyone He sees, He even Loves to Wave to You too!!

Even all those with Autism and Disabilities and Special Needs show Happiness and Care and Kindness in so many different Ways.

I love to Wave and Smile to Everyone I see because it is one of the ways that I love to show Joy and Care and Kindness and Happiness too.



**Kevin Hosseini**



Bella

I like to paint with thick paint. This is my favorite dog Bella who I used to play with. Bella was my tutor Keith's dog. Keith worked for the Koegel Autism Center.

**Noah Schneider**

My autism has influenced my art because my disability makes me think of creative ideas from my imagination that other people do not think of. I think differently from kids who don't have autism because I already know what I want to do in my future. In general, a lot of kids who don't have autism don't know what to do with their lives. I started loving art when I was in 7th grade in Middle School. Everyday throughout my life I always create art and I like anything that deals with art.



60s Still Life



Peanut Butter

**Emily Casanova**



Dying



Beautiful Ladies



Beluga Whale



## Observation and Imagination

by Kay Aitch

During encounters with drunken old men on trams, who grasp my hand and ramble in slurred speech, I explain that I am a surrealist. If the drunk knows nothing about this he holds my hand tighter still, leans forward and nods knowingly; if the drunk knows something about art he lets go of my hand and leans back quietly—realizing that I am probably weird.

For me, being a surrealist means encountering everyday life with an exuberance of curiosity, excitement, and fear, along with an unexplainable but overwhelming desire to communicate with others through art. The intention is not for others to understand me but in the hope of connecting with the viewer on a level deeper than conscious rational thought.

I work across a variety of media; I do however have a preference for working with or on paper in some way. My preliminary work is often an expression of my day-to-day experience, which I record through drawing and photography—sketchbook and camera notes that I often process on the computer as ideas develop—maybe then through paint, digital print, sculpture, a textile piece, or an interweaving of techniques. I produce work for exhibition, commission, illustration, and installation.

I often use the technique of drawing without looking at the paper, as this helps me to concentrate much more closely on observing the subject of my drawing. Developing the ability to observe more closely helps to excite my imagination and inspire my creativity. Drawing helps me to focus in the moment, as with the concept of mindfulness. It is therefore the foundation of the workshops which I run—Drawing for Well Being.



Hand with Eyes

I think of my self portrait as being of my hands—I can see my hands, they are my direct contact with the world, whereas I only see my face in the mirror.

**D.J. Svoboda** is a public speaker, artist, and author with three books to his credit: *My Imagiville*, *The Mupperezmo and the Rainbow*, and *The Inspirations of Imagiville*. D.J.'s artwork has been featured in *Autism Spectrum*, *Autism Digest*, *Autism Perspective*, and *Australian Parent's Child*, among other publications, and hangs in museums and on the walls of corporations, organizations, and private homes. D.J. has been nominated for the Naturally Autistic ANCA Visual Arts Award and been interviewed on numerous radio and television shows. He is an advocate for the North Carolina Autism Society and has been the keynote speaker at various autism conferences, meetings, and events all over the country.

**Kevin Hosseini** is an artist on the autism spectrum who resides in El Cajon, California. His artwork has been displayed in many galleries and museums, including the Smithsonian Institution.

**Noah Schneider** is an artist and character designer whose animated films have won several awards.

**Emily Casanova, PhD**, is a developmental, molecular, and cell biologist who studies autism, intellectual disability, epilepsy, and schizophrenia and enjoys photography in her spare time. Emily was diagnosed with Asperger syndrome in 2007.

**Kay Aitch** is an artist who leads workshops entitled "Drawing for Well Being" that explore the relation between creative expression and health.

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## SECOND THOUGHTS

### Complementary and Alternative Treatments for Autism Part 1: Evidence-Supported Treatments

Stephen Bent, MD, and Robert L. Hendren, DO

*Editor's note: This is the first of a two-part series. Read [Part 2](#).*

Autism is a complex neurodevelopmental disorder characterized by marked impairments in the ability to interact socially combined with restrictive, repetitive patterns of behavior. Only a few decades ago, the disorder appeared to be relatively uncommon, with a reported prevalence of roughly 3 in 1,000 children prior to 1990 [1]. The most recent prevalence estimate from 2010 indicates that it affects 1 in 68 children in the US [2]. Autism often has profound negative impacts for affected children, their families, and their communities. Most children with moderate to severe autism spectrum disorder will have lifelong impairments in social skills; difficulties in school; cognitive challenges; increased rates of anxiety, depression, and obesity; and decreased rates of employment and independent living [3]. Family members also have higher rates of anxiety, stress, mental illness, and lost productivity due to their child's special needs [4].

Unfortunately, effective treatments for autism have been elusive. The mainstay of therapy is intensive behavioral intervention—given for 20 or more hours per week—which has been shown to produce important benefits, but response to treatment varies widely, and it is challenging to predict which children will respond [5]. Only two drugs have been approved by the US Food and Drug Administration for the treatment of autism—risperidone and aripiprazole—and both target an associated behavior problem, irritability, rather than the core deficits in social skills and repetitive behavior [6]. Both drugs also have significant side effects, including weight gain and sedation.

It is no surprise, therefore, that parents seek complementary and alternative medicine (CAM) therapies to try to help their affected children. Numerous surveys of parents have found that a very high percentage of children with ASD—up to 95 percent in one study—were using CAM therapies for general health or to improve symptoms of ASD or associated symptoms such as irritability, hyperactivity, GI problems, and sleep disturbances [7-9]. Initially, many considered the therapies classified as CAM to be ineffective, sometimes dangerous, often expensive, and potentially distracting for parents, who often implement the time-consuming but sometimes ineffective behavioral programs. Secretin, for example, is an expensive intravenous drug that was studied in seven randomized controlled trials before all the evidence was systematically

reviewed and it was conclusively determined to be ineffective [10]. Chelation therapy is a CAM treatment promoted to remove heavy metals from the blood; it can be dangerous and there is no convincing evidence of efficacy [11]. These high-profile examples of ineffective or dangerous CAM therapies led to a general mistrust of and distaste for anything believed to be a CAM treatment for ASD.

### **CAM for Abnormal Physiology**

But the tide is beginning to shift as evidence accumulates that some CAM therapies are addressing abnormal physiology in autism. Autism is now known to be associated with a number of physiological abnormalities that have been classified into four broad categories: oxidative stress, inflammation or immune dysregulation, mitochondrial dysfunction, and environmental toxicant exposure [12]. CAM therapies that improve these physiological abnormalities hold promise for improving symptoms. Extensive reviews of the evidence for all CAM therapies in ASD have recently been published [13], and a few compelling examples are worthy of discussion.

Oxidative stress refers to an imbalance in the generation and detoxification of reactive oxygen and nitrogen species, mediators known to be associated with cell damage. These reactive oxygen species are a normal part of human physiology, but, if they are not removed appropriately, they accumulate and lead to protein, DNA, and cell damage. Several investigations have found evidence of abnormal oxidative stress in children with autism, including laboratory biomarkers of decreased antioxidant enzymes (e.g., superoxide dismutase, transferrin, and ceruloplasmin) and elevations in biologic measures of oxidative stress (including increased lipid peroxidation and impaired plasma methionine methylation capacity) [14, 15]. Whether abnormal biomarkers indicate a cause or are an effect of autism is not known. Regardless, children with autism who have more oxidative stress have been found to have more severe symptoms [16].

Two CAM treatments—N-acetylcysteine (NAC) and methylcobalamin (B12)—target the problem of oxidative stress. NAC is available over the counter and, when given systemically, acts as a direct antioxidant and an efficient prodrug (an inactive drug converted to an active substance by the body's metabolic processes) for cysteine, which is a key component of the antioxidant system in the body [17]. A recent, small 12-week randomized placebo-controlled trial showed that NAC is able to reduce irritability in children with autism [18], as are the two approved antipsychotic drugs [19, 20], but with no observed side effects.

Vitamin B12 is a vital cofactor in the antioxidant system that spurs the regeneration of methionine from homocysteine. In a small pilot randomized controlled trial of 30 children with ASD, B12 injections did not improve overall outcomes, but a subset of children supplemented with B12 showed improvements in both measures of oxidative stress and clinical symptoms [21]. This result led to a recent, larger randomized controlled trial that

has been completed by our group at the University of California, San Francisco, and initial (unpublished) results suggest that B12 is also effective in improving overall symptoms. Together, the early studies of NAC and B12 are promising examples of CAM therapies that accord with physiological models and are supported by initial evidence.

Inflammation, too, has been shown to respond to a CAM treatment. Perhaps the most exciting treatment study in autism published recently involved a mouse model and treatment with probiotics [22]. Pregnant mice were injected with a chemical (polyinosinic-polycytidylic acid) that stimulates a response similar to a viral infection, which reliably produces infant mice with symptoms that mimic human autism including impaired ability to socialize and repetitive behaviors. Affected mice were also found to have increased intestinal permeability, sometimes referred to as “leaky gut,” which was measured by what occurs when inflammation, which interferes with the normal “tight junction” of the intestinal epithelium, allows large molecules to cross into the bloodstream. The investigators found that treating these mice with a probiotic (*Bacteroides fragilis*) led to a resolution of the leaky gut (the large molecules were no longer found in the blood); a restoration of normal intestinal flora; and a reduction in anxiety behaviors, communication abnormalities, and stereotypical behaviors. Even more fascinating, the authors then injected into normal mice one of the molecules that was markedly elevated in the blood when the mice had a leaky gut—a metabolite known as 4-ethylphenylsulfate (4-EPS). Mice injected with 4-EPS demonstrated anxiety-like behaviors similar to those seen in the mouse autism model. Although a mouse model clearly does not directly translate to humans, this elegant study provides support for the theory that the abnormal gastrointestinal function so commonly seen in children with autism [23] may contribute to or even cause some of the symptoms.

### **Conclusion**

The use of CAM treatments for autism has been based upon the premise that there are physiological abnormalities in autism, and that if these can be corrected or improved, symptoms may also improve. This is sound reasoning, and some have suggested that the term CAM should be replaced by the term “biomedical” to reflect the underlying goal of treating abnormal biomedical function, as with pharmaceutical drugs. Physiological abnormalities have been shown to be present in autism, and preliminary evidence suggests that correcting them may produce important benefits. Whether one calls them CAM therapies or biomedical therapies, we support the further rigorous, evidence-based investigation of treatments that address physiological abnormalities. It is ethical for physicians to support families considering plausible CAM treatments after a thorough exploration and discussion of potential mechanisms of action, benefits and harms, safety, expense, and how use of these CAM treatments might compete for time and resources with other behavioral interventions. Clearly, we must be cautious not to prematurely recommend therapies that have no or limited evidence, but, when they are

held to evidence-based standards, there's really nothing all that "alternative" about CAM treatments.

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**Stephen Bent, MD**, is an associate professor of medicine, psychiatry, and epidemiology and biostatistics at the University of California, San Francisco, School of Medicine. His current research focuses on the safety and efficacy of complementary and alternative medical (CAM) therapies in children with autism, clinical trial design including use of the Internet to facilitate research, and systematic reviews of clinical trials.

**Robert L. Hendren, DO**, is a professor of psychiatry and behavioral science, the director of child and adolescent psychiatry, and vice chair of the Department of Psychiatry at the University of California, San Francisco, School of Medicine. His research and publication interests are in translational clinical pharmacology and nutraceutical and nutritional trials

using biomarkers (MRI, measures of inflammation, oxidative stress, immune function, and pharmacogenomics) to enhance resilience in neurodevelopmental disorders.

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## SECOND THOUGHTS

### Complementary and Alternative Treatments for Autism Part 2: Identifying and Avoiding Non-Evidence-Based Treatments

Alison Singer, MBA, and Ramita Ravi

*Editor's note: This is the second of a two-part series. Read [Part 1](#).*

The pace and progress of autism research has increased dramatically over the past five years. Yet, despite these advancements, we have not yet identified a singular cause of or cure for autism. Consequently, some parents fall victim to the allure of unproven complementary and alternative medicine, known as CAM, as potential remedies for their children's symptoms.

Although a wide spectrum of therapeutic practices exists, there are four major domains of CAM autism treatments: mind-body medicine interventions (intended to target interactions between brain and behavior), biology-based treatments (proffering natural substances as treatment alternatives), manipulative and body-based practices (that attempt to treat conditions through body manipulation), and energy medicine ("channeling energy" to promote healing). Common CAM techniques for treating autism include dietary supplements, vitamins, hyperbaric oxygen, hormone injections, swimming with dolphins, horseback riding, yoga, and massage. While these remedies may seem enticing and low-risk, there is not enough evidence to suggest that they effectively reduce symptoms of autism. Furthermore, some of these non-evidence-based treatments can be downright dangerous.

Studies show that 50-75 percent of children with autism use some CAM in an effort to improve symptoms [1, 2]. Approximately half of these children use biology-based therapies, 30 percent use mind-body therapies, and 25 percent use manipulation or body-based therapies [2]. In our opinion, most families try CAM because they hear about it in the media, perceive it as "natural," and are eager to leave no stones unturned in their efforts to manage autism symptoms. Very few studies have proven the efficacy of these kinds of CAM in alleviating symptoms of autism. Doctors must direct parents away from non-evidence-based practices that may be detrimental to children's health.

Many CAM practices are based on misguided theories about the causes of autism. The rationale for diets free of gluten (protein found in wheat, rye, and barley) and casein (protein found in dairy products), for example, is the claim that children with autism have "leaky guts" that allow opioids from these proteins to enter the bloodstream, travel into

the brain, and cause autistic behaviors [3]. Yet, research has consistently demonstrated no difference between bloodstream opioid levels in individuals with autism and in neurotypical individuals [4, 5]. What has been proven by research is that a gluten- and casein-free diet is related to lower bone density, which can lead to osteoporosis [6]. Studies testing the efficacy of a gluten-free and casein-free diet in treating autism using randomized, double-blind, repeated measure crossover designs have yielded no statistically significant findings, even though several parents reported improvement in their children [7, 8].

Chelation therapy is another CAM practice that is based on an unproven notion of what causes autism. During chelation therapy, chemicals are administered that bind to heavy metals, such as mercury, and eliminate them from the body. However, there is no evidence that autism is caused by heavy metal poisoning, nor are there any controlled studies that show this practice to be safe or effective. In fact, in 2005 a child died when a chelating agent bonded with calcium and caused the child's heart to stop [9].

Lupron therapy is also offered in a misguided attempt to cure what doesn't actually cause autism. Lupron is a testosterone-inhibiting drug used to treat prostate cancer and precocious puberty. Use of Lupron in children with autism is based on the notion that testosterone magnifies the effect of mercury and that reducing testosterone would reduce the effects of mercury [10]. There are no studies indicating mercury causes autism or that mercury bonds to testosterone. Lupron also has many harmful side effects including numbness, weakness, difficulty breathing, trouble swallowing, hives, blood in the urine, bone pain, testicular pain, and osteoporosis [11].

It is important to note that risky CAM treatments are not limited to drugs. Holding therapy, for example, is a manipulative, body-based therapy that stems from the erroneous notion that autism is caused by a parent's failure to bond with his or her child [12]. In a holding therapy session, caregivers physically restrain children and force eye contact, hoping to repair the emotional detachment [13]. Because of the intense physical pressure applied by caregivers, this practice is risky and has even led to fatalities [14]. This treatment is dangerous, there is no evidence to support its efficacy, and it is founded upon a hypothesis inconsistent with medical models [13].

### **Identifying an Unsupported CAM Treatment**

Unfortunately, there are many unscrupulous charlatans who are eager to take advantage of parents desperate to try anything that sounds like it might help their children with autism. We receive several emails a week from practitioners offering "the cure" for autism (often for the "low, low price" of \$299). We are often horrified at how these emails use guilt and guile to encourage families to try these untested treatments because "if you really loved your child, wouldn't you want to leave no stone unturned?"

At the Autism Science Foundation, we urge parents to be particularly wary of untested treatments and of practitioners who are unwilling to submit their treatments to the rigor of a double-blind, randomized, placebo-controlled trial. Many practitioners of these supposed cures will say things like “I know it works,” “I’ve seen it work,” or “I don’t want to spend time and money testing it when it could be helping children right away.” We urge parents to run, not walk, away from any treatment that claims to be too good for science.

When studies of a treatment are published, both physicians and parents need to look carefully to be sure that they are published in a reputable peer-reviewed scientific journal. Not all journals are created equal; the Internet has made it possible for anyone to publish a “journal,” and paid search optimization has made it easy for anyone to make their study appear first in a Google search. But a journal published online by the scientist in her basement that is “peer-reviewed” by her cousin is not the same as a study published in a high-impact, reputable medical journal edited and peer-reviewed by proven leaders in the field.

Even studies published in reliable journals should be questioned. A treatment that is truly effective will be backed up with clear evidence and proper methodology. In intervention studies, appropriate methodology includes the use of well-matched control groups, pre- and post-treatment testing, representative samples, sufficient sample sizes, random assignment, and procedures to eliminate bias. In intervention testing for autism, control groups should be matched according to sex, age, diagnosis, and functionality. Additionally, in order to eliminate bias, both investigators and participants should be “blinded” and remain unaware of whether a participant is receiving a placebo or treatment.

Publications of research that demonstrate positive results for a treatment are often unlikely to highlight any methodological flaws in the studies. That’s why parents and doctors should review methodology and look carefully at study design and execution. For example, vitamin B6 and magnesium dietary supplements have been a popular treatment for autism for the past 20 years [6]. Three controlled studies published between 1993 and 2002 claimed that B6 and magnesium were effective treatments for autism. However, in a recent literature review, Susan E. Levy, MD, of Children’s Hospital of Philadelphia and Susan Hyman, MD, of University of Rochester Medical Center pointed out that all three studies had inadequately described the diagnosis of autism and had failed to establish proper “selection criteria and outcome measures” [6]. They concluded that, because of the small number of studies and their improper methodology and small sample sizes, there was not adequate evidence to support the use of these treatments.

Parents and physicians also need to read studies carefully to determine whether the study provides evidence that a particular treatment alleviates symptoms specific to

autism. For example, studies show that yoga, a mind-body CAM practice, reduces anxiety [15]. But there is no evidence and no reason to believe that yoga affects individuals with autism who are not also diagnosed with anxiety any differently than it affects children with other types of disabilities or with no disabilities. Yet, practitioners tout yoga as a treatment for autism [16].

### **Conclusion**

While many CAM practices sound harmless enough, many are dangerous as well as ineffective. Parents want to do everything they can to help their children with autism, but unstudied and ineffective CAM practices are simply not worth the high risk or cost.

Fortunately, we do have good evidence-based treatments that have been proven to mitigate symptoms of autism, including applied behavior analysis, speech therapy, occupational therapy, and physical therapy. There are currently two medications approved by the US Food and Drug Administration (FDA) for symptoms associated with autism [17], and FDA-approved human clinical trials are testing medications that target the core symptoms of autism, including social and learning disabilities and language development [18]. Reliable treatments should affect specific symptoms of autism while minimizing risk to the individual. All treatments should be subjected to the rigor of well-designed, double-blind, placebo-controlled clinical trials.

Most parents are not trained scientists. It is largely up to physicians to steer parents away from these risky, ineffective, untested practices. It is the physician's responsibility to encourage families to seek safe, effective, evidence-based interventions.

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**Alison Singer, MBA**, is co-founder and president of the Autism Science Foundation in New York City and serves as a public member of the federal Interagency Autism Coordinating Committee (IACC), which writes the annual strategic plan to direct federal spending for autism research. She has a 17-year-old daughter with autism and an older brother with autism. She is a graduate of Yale College and Harvard Business School.

**Ramita Ravi** is an undergraduate at the University of Pennsylvania in Philadelphia where she is majoring in health and societies with a concentration in public health.

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## Suggested Readings and Resources

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## About the Contributors

### Theme Issue Editor

Kathleen K. Miller, MD, is a first-year resident in pediatrics at the University of Wisconsin in Madison. She graduated in 2014 from the Carver College of Medicine in Iowa City, Iowa, and will be pursuing general pediatrics.

### Contributors

Kay Aitch is an artist who leads workshops entitled "Drawing for Well Being" that explore the relation between creative expression and health.

Thomas Armstrong, PhD, is the executive director of the American Institute for Learning and Human Development in Cloverdale, California. He is the author of 15 books, including *The Power of Neurodiversity: Unleashing the Advantages of Your Differently Wired Brain* (Da Capo Press, 2011) and *Neurodiversity in the Classroom: Strength-Based Strategies to Help Students with Special Needs Succeed in School and Life* (ASCD, 2012). His books have been translated into 26 languages, and he has lectured on learning and human development themes in 44 states and 25 countries over the past 29 years.

Rebecca Benson, MD, PhD, is the medical director of the Pediatric Pain and Palliative Care Program at the University of Iowa Children's Hospital and the director of the ethics consult service at the University of Iowa Hospitals and Clinics in Iowa City. She is passionate about providing support to children and families experiencing serious illness and educating health care professionals about palliative care and ethics.

Stephen Bent, MD, is an associate professor of medicine, psychiatry, and epidemiology and biostatistics at the University of California, San Francisco, School of Medicine. His current research focuses on the safety and efficacy of complementary and alternative medical (CAM) therapies in children with autism, clinical trial design including use of the Internet to facilitate research, and systematic reviews of clinical trials.

Jeffrey P. Brosco, MD, PhD, is a professor of clinical pediatrics and associate director of the Mailman Center for Child Development at the University of Miami Miller School of Medicine and chair of the Pediatric Bioethics Committee at Jackson Memorial Hospital in Miami, Florida. Board-certified in pediatrics and developmental-behavioral pediatrics, he completed his tenure as a Robert Wood Johnson Generalist Faculty Scholar in 2003 after earning an MD and a PhD in the history of medicine at the University of Pennsylvania. With Diane Paul, he co-authored *The PKU Paradox: A Short History of a Genetic Disease* (Johns Hopkins University Press, 2013). Dr. Brosco's research includes analysis of the

history of health care for children in early twentieth-century Philadelphia, the historical epidemiology of intellectual disability, and the history of newborn screening in the US.

Emily Casanova, PhD, is a developmental, molecular, and cell biologist who studies autism, intellectual disability, epilepsy, and schizophrenia and enjoys photography in her spare time. Emily was diagnosed with Asperger syndrome in 2007.

Nanette Elster, JD, MPH, is a lecturer in the Neiswanger Institute for Bioethics and Health Policy at Loyola University Chicago Stritch School of Medicine. She has extensive experience in legal, public health, and ethical issues related to women's and children's health.

William D. Graf, MD, is professor of pediatrics (neurology) and neurology (child neurology) at Yale School of Medicine in New Haven, Connecticut. Dr. Graf is the chair of the Child Neurology Society (CNS) Ethics Committee and an active member of the American Academy of Neurology (AAN) Ethics, Law, and Humanities Committee. His clinical and research interests focus on all aspects of brain development.

Robert L. Hendren, DO, is a professor of psychiatry and behavioral science, the director of child and adolescent psychiatry, and vice chair of the Department of Psychiatry at the University of California, San Francisco, School of Medicine. His research and publication interests are in translational clinical pharmacology and nutraceutical and nutritional trials using biomarkers (MRI, measures of inflammation, oxidative stress, immune function, and pharmacogenomics) to enhance resilience in neurodevelopmental disorders.

Dien Ho, PhD, is an associate professor of philosophy and healthcare ethics at Massachusetts College of Pharmacy and Health Sciences University (MCPHS) in Boston. His research interests are reproductive ethics, theories of explanation, pharmaceuticals and philosophy, and clinical ethics.

Kevin Hosseini is an artist on the autism spectrum who resides in El Cajon, California. His artwork has been displayed in many galleries and museums, including the Smithsonian Institution.

Annemarie M. Kelly, JD, LLM, serves as counsel in the Medicaid Third Party Liability Division of the Michigan Department of Community Health in Lansing. She has practiced on behalf of physicians and hospitals in Michigan, Illinois, and Iowa in medical malpractice and contract dispute cases. A staunch advocate for community health issues, Annemarie volunteers for multiple child health services organizations in the greater Chicago and Lansing areas. She received her JD from Drake University and her LLM fellowship degree in health law from the Loyola University Chicago School of Law.

Nili E. Major, MD, is a developmental-behavioral pediatrician at the North Shore-LIJ Cohen Children's Medical Center in New Hyde Park, New York. Her professional interests include resident education in developmental-behavioral pediatrics.

Jill Mullin, MA, MEd, is a board certified behavior analyst and the regional coordinator for Applied Behavior Consultants, Inc., in Portland, Maine. She holds a master's degree in general and special education from Touro College and a master of arts degree in psychology with a concentration in applied behavior analysis from the University of the Pacific. She has worked closely with individuals diagnosed with autism and their families for 15 years.

Jody R. Murph, MD, MS, is an associate professor of pediatrics at the University of Iowa Children's Hospital and has secondary appointments in the College of Public Health, the Department of Epidemiology, and the College of Law at the University of Iowa in Iowa City. Her interests include vaccine development and controversies, health policy, and the importance of social determinants of health on early child development.

Kayhan Parsi, JD, PhD, is a professor and the director of graduate studies in the Neiswanger Institute for Bioethics and Health Policy at Loyola University Chicago Stritch School of Medicine. His research interests are in clinical ethics, ethics education, global health, and professionalism and professional ethics.

Catherina Pinnaro, MD, is a pediatric resident at the University of Iowa Hospitals and Clinics in Iowa City. She plans to pursue fellowship training in medical genetics. Her research interests include ethical issues associated with clinical exome sequencing and reporting of incidental findings.

Ramita Ravi is an undergraduate at the University of Pennsylvania in Philadelphia where she is majoring in health and societies with a concentration in public health.

Matthew A. Rysavy is a medical student and PhD candidate in epidemiology at the University of Iowa Carver College of Medicine in Iowa City, where he is active in the design and implementation of the evidence-based medicine curriculum. His interests include child health, research methods, and science education.

Noah Schneider is an artist and character designer whose animated films have won several awards.

Alison Singer, MBA, is co-founder and president of the Autism Science Foundation in New York City and serves as a public member of the federal Interagency Autism Coordinating Committee (IACC), which writes the annual strategic plan to direct federal

spending for autism research. She has a 17-year-old daughter with autism and an older brother with autism. She is a graduate of Yale College and Harvard Business School.

D.J. Svoboda is a public speaker, artist, and author with three books to his credit: *My Imagiville*, *The Mupperezmo and the Rainbow*, and *The Inspirations of Imagiville*. D.J.'s artwork has been featured in *Autism Spectrum*, *Autism Digest*, *Autism Perspective*, and *Australian Parent's Child*, among other publications, and hangs in museums and on the walls of corporations, organizations, and private homes. D.J. has been nominated for the Naturally Autistic ANCA Visual Arts Award and been interviewed on numerous radio and television shows. He is an advocate for the North Carolina Autism Society and has been the keynote speaker at various autism conferences, meetings, and events all over the country.

Mitzi M. Waltz, PhD, is an associate lecturer in autism studies at the Autism Centre, Sheffield Hallam University, in Sheffield, UK, and a senior researcher for Disability Studies in Nederland in Amersfoort and at Rotterdam University of Applied Sciences in The Netherlands. Her interests are in the history of autism, media and clinical representations of disability, and improving life outcomes for people with autism and their families.