Unorthodox Theories of Autism Are Wrong and Inhuman

A review of

Defeating Autism: A Damaging Delusion
by Michael Fitzpatrick

Reviewed by
Stuart W. G. Derbyshire

At the end of the 1970s, Wing and Gould (1979) identified clusters of features that, combined, they considered to be diagnostic of autism: deficits in social interaction (aloofness, indifference, passivity, and “odd” interactions), in communication (no language or deviant language, including repetitive, stereotypical, or echoed speech), or in imagination (an inability to engage in pretend play, rigid or ritualistic thought and behavior). This triad of features rationalized the diagnosis of autism. Children with the features described by Wing and Gould were previously diagnosed as psychotic, schizophrenic, or having schizoid personality disorder but were gradually coming to be diagnosed as autistic.

This rationalization of diagnosis was important and provided a rich theoretical framework to study and understand autism. In particular, describing the distinctive nature of autism simplified investigation of the precise biological and cognitive abnormalities
underlying autism. Genetic or neurodevelopmental problems were widely assumed to cause these abnormalities.

In *Defeating Autism: A Damaging Delusion*, Michael Fitzpatrick describes how the unorthodox biomedical movement, both in Britain and the United States, “seeks to redefine autism as an epidemic disease caused by vaccines or some other, as yet unidentified, environmental factor” (p. xv). In Fitzpatrick’s view, this movement is disastrous for those with autism and their families and an unwelcome and unwarranted distraction for those who investigate autism.

Fitzpatrick is well placed to comment on these issues. He has been a family doctor in East London for 25 years, and he has a teenage son with autism. After the diagnosis of his son, Fitzpatrick began to read the scientific literature on autism. He and his wife also began to network with other families who had a child with autism. When Fitzpatrick’s medical status became known, he was asked to comment on various new ideas about the causes of autism and the potential for innovative cures. Fitzpatrick was briefly curious, but to say I was disappointed would be an understatement. What immediately struck me about the writings of Shattock and Rimland and their colleagues was that, rather than indicating an innovative approach at the cutting edge of medical science, they revealed a retreat into the by-ways and cul-de-sacs of the biological psychiatry of the 1960s and the 1970s. Shattock’s dietary focus could be traced back to the work of the American psychiatrist Curtis Dohan who, in the 1960s, postulated that the low rates of schizophrenia he discovered in the South Pacific might be related to the lack of dairy and wheat products in the local diet. Yet, other studies failed to confirm this link. (p. x)

Fitzpatrick goes on to explain that those in the unorthodox biomedical movement and members of the Defeat Autism Now! (DAN!) network rarely publish in peer-reviewed literature, preferring, instead, the “gray” literature of vanity publishing houses. And their grandly named research institutes are rarely more than campaign headquarters that produce press releases but nothing that could be described as research or scholarship.

Moreover, encounters with the unorthodox biomedical movement are typically costly. Secretin injections from a private doctor in London will result in significant financial hardship for a family on benefits as well as inevitable disappointment when the injections turn out not to be a miracle cure. Such encounters can also cost a lot more than money. In 2005, Tariq Nadama, a five-year-old British boy with autism, went to America for metal detoxification with chelation therapy—a treatment he did not need and that would not work even if he did. Tariq died.

Why are parents of autistic children subjecting their children to costly treatments that cannot work and may have significantly negative effects? Fitzpatrick identifies several key developments in answer. First is the undeniable fact that the unorthodox biomedical movement has had a notable impact. In 1998, Andrew Wakefield was the lead author of an
article in the widely respected, widely cited, and peer-reviewed journal *Lancet*, postulating a link between the measles–mumps–rubella (MMR) vaccine and the onset of autism. In 1999, the U.S. child immunization program began removing thimerosal (containing mercury) from vaccines because thimerosal-containing vaccines had been linked with large increases in the diagnosis of autism during the previous 10 years. An inquiry conducted by the University of California Medical Investigation of Neurological Disorders (M.I.N.D.) Institute concluded in 2002 that this increase in diagnosis could not be explained by changes in diagnostic criteria (Byrd, 2002). Antivaccine campaigners seized upon the implication that the cause was thimerosal.

A series of studies and accusations of misconduct and fraud have seriously undermined Wakefield’s attempt to link MMR with autism (Baird, Cass, & Slonims, 2003). Most of Wakefield’s coauthors withdrew their support of the original article in 2004. The apparent link between thimerosal and autism was similarly undermined by a continued rise in autism rates long after the complete withdrawal of thimerosal from vaccinations in 2001. The increased prevalence of autism was attached to better recognition and diagnosis of autism and broadening scope of the diagnosis.

Second, Fitzpatrick recognizes a palpable suspicion, sometimes outright hostility, against mainstream science and medicine. It is no longer unusual for people with chronic illnesses to turn to an alternative practitioner for medical advice. Other commentators have lamented the rise of alternative practitioners making overblown claims for natural treatments such as herbs and vitamins (Goldacre, 2008).

But Fitzpatrick goes further by pointing out that the claims of alternative practitioners dovetail with a disdain for modernity. There is a widespread perception of risk from an unprecedented array of hazards, including pesticides, organophosphates, dioxins, metals, flame retardants, polychlorinated biphenyls (PCBs), phthalates, ozone, microbial agents, electromagnetic fields, and so on. At various times, various campaigners connect one or more of these hazards with any number of diseases, including autism.

The connection is almost always tenuous, unsubstantiated, and arbitrary but is accepted, even if only temporarily, because of the perception that we are at risk and that children, especially infants, are uniquely vulnerable to such risk. There is also, sadly, a strong reluctance on the part of scientists to openly challenge such pseudoscientific claims because of fear that a frank debate may not be effective, may alienate parents and patients, or may undermine access to funding.

Finally, Fitzpatrick points to the increased acceptance of the idea that autism exists on a continuum, which can romanticize autism as a “difference” rather than being a psychiatric condition and encourages an expansion of diagnosis. Understanding autism as a continuum reduces marginalization of people with autism and allows for a broader understanding of symptoms on an autistic spectrum. But, as Fitzpatrick explains,
the tendency to label as autistic every absent-minded professor and eccentric scientist, and
every obsessive engineer, train-spotter and stamp-collector . . . carries the danger that the
spectrum becomes stretched so wide that autism loses its distinctiveness. “Normalising”
autism may reduce stigma, but at the risk of trivialising the problems of those with more
severe cognitive deficits and also of underestimating the extreme aloneness that results
from the social impairment of autism, even in higher-functioning individuals. (p. 36)

Normalizing autism also means that people are more willing to accept a diagnosis of
autism both for their children and for themselves. An autism diagnosis becomes an identity,
a way of making sense of a confusing world, and provides various privileges and
entitlements. Diagnostic expansion also creates the illusion of a hidden epidemic that must
have a cause and must be addressed.

Fitzpatrick’s aim in writing this book is “to avoid the diversions and dead-ends
offered by the perspective of ‘defeating autism’” (p. xviii). One book won’t manage that, but
Fitzpatrick has begun a much-needed conversation. It is important to recognize that the
unorthodox biomedical movement is not just an irritation but a divisive and destructive force
that threatens to derail autism research and undermine the quality of life that children with
autism can enjoy.

Because the unorthodox biomedical movement views children with autism as polluted
rather than as suffering a neurodevelopmental disorder, there is a strong tendency toward an
overwhelmingly negative attack against autism. This attack easily becomes an attack against
the child, who is dehumanized in the attempt to find the “real” child lurking beyond the
“polluted” child. Parents subject their children to unpleasant and restrictive diets, provide
them with endless vitamin and herbal supplements, and subject them to invasive tests and
treatments that are unnecessary and disturbing.

This might sound innocuous enough, but refusing an autistic child his or her favorite
foods to comply with an unwarranted diet can lead the child toward malnutrition. Getting an
autistic child to swallow a tablet that he or she doesn’t want (and that has no medicinal or
therapeutic value) can involve considerable physical force. And taking an autistic child to an
unfamiliar hospital setting for an invasive test that offers no benefit to the child can cause
considerable stress and behavioral regression.

A final case from Fitzpatrick forcefully illustrates the potential inhumanity of
unorthodox intervention. In September 2007, the British *Sunday Times Magazine* published
the story “Quest for a Miracle Cure” (Rayment, 2007). Rowan, the six-year-old autistic son
of journalist Rupert Isaacson and psychologist Kristen Neff, had been taken to Mongolia to
be with horses and undergo therapy with shaman healers. This followed months of other
failed therapies, including speech and occupational therapy, applied behavior analysis,
chelation, and various chemical and vitamin supplements.

When we pick the story up, Rowan is in distress and refusing to go near a horse,
despite having previously interacted happily with horses. Why the sudden reluctance? Well,
“two days earlier he [had] been subjected to what looks to an outsider like child abuse. He [had] been whipped by a shaman—an intermediary between the natural and spirit worlds—and force-fed milk, then held under a noisy drum” (Rayment, 2007, ¶ 20).

As Fitzpatrick notes, “We can agree, ‘to an outsider’ this certainly looks like child abuse” (p. 47). When autism is wrongly perceived as the product of some toxin that must be rooted out to save the child, then “therapy” can easily veer from conventional to alternative to inhuman. When an apparent growing epidemic is connected to unreal concerns about modernity and disconnected from facts, then debate can easily veer from criticism to cynicism to conspiracy. A disembodied attitude of incredulity toward what is known and true can lead parents and scientists to dark places. Fitzpatrick’s book is a superb effort to reverse these negative trends.

References


