



Letter to the Editor: An Autism Parent's Response to Papatola and Lustig's Paper on Navigating a Managed Care Peer Review in *Behavior Analysis in Practice*

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Published online: 5 June 2018
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Abstract

An autism parent disputes the authors' premise that the role of the BCBA is to "transition treatment to parents." Parents cannot simply "take over" all the advanced degrees, thousands of hours of coursework practicum and exams, or depth and breadth of scientific knowledge required to earn a BCBA any more than we can (or should) "take over" our kids' pediatric care or prescribe their meds. Papatola and Lustig's employer, Cigna Behavioral Health, recently made "transition treatment to parents" a criterion of medical necessity for ABA.

Keywords Autism · Insurance · ABA · BCBA · Autism-mom

Editor's Note The editorial staff of Behavior Analysis in Practice (BAP) would like to note that none of the opinions of the following letter, the Papatola and Lustig (2016) article to which it refers, nor any other articles published in BAP are the opinions of BAP or the Association for Behavior Analysis International. Furthermore, it is unusual for BAP to publish letters to the editor, but the particular issues being addressed here are of significant impact for behavior analysts and the families they serve. We invite further comments from readers, be they behavior analysts, client families, or third-party payers.

I write to respond to the paper "Navigating a Managed Care Peer Review: Guidance for Clinicians Using Applied Behavior Analysis [ABA] in the Treatment of Children on the Autism Spectrum," published in *Behavior Analysis in Practice* on April 1, 2016. The authors summarize:

In summary, discharge (or termination) is a misnomer. It is better described as transitioning the program from the therapist to the parents and the community. As with learning to ride a bicycle ... the parent prepares the child

... then serves as the *balance* until the child masters riding on his own. So too does the BCBA and treatment team offer appropriate *equipment* by giving parents the skills. . . . Over time, parents are able to take over for the BCBA and treatment team.

The authors, Drs. Papatola and Lustig, neither of whom is a **Board Certified Behavior Analyst (BCBA)**, assert that ABA is like riding a bike, and that the role of a BCBA is "transitioning the program ... to the parents and the community." They're not talking about parents supporting ABA, participating actively in sessions and clinic meetings, identifying targets and opportunities, generalizing and maintaining skills acquired, and keeping the funding tap turned on somehow—all of which are necessary expectations of a family with a child in ABA. They explicitly require that the child's family *supplant*, not just *support*, the professional treatment team.

Follow that logic if you can, BCBAs: All your multiple advanced degrees, your thousands of hours of coursework and practicum and exams, the depth and breadth of your scientific knowledge, and your sense of vocation in working with autistic children, all must be "transitioned" to each autism family on your caseload, as easily as riding a bike. If you're any good at your job, "parents and the community" will take over all that you do, and continue treating each patient with amateur behavioral interventions, for free! Is that plausible, or insurance-company wishful thinking?

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Cigna Behavioral Health, the employer of both aforementioned authors, cut off funding for my autistic son's ABA in January 2015, alleging failure to meet medical necessity, based on exactly the thesis of the aforementioned article. Case management record entries in my son's file beginning in November 2014 demand (in boldface capital letters) to know why his parents have not been trained to replace his professional treatment team.

Then came this new Criterion of Medical Necessity added by Cigna on January 1, 2015: "Goals must be designed to transition treatment to parents or caregivers." Days later Cigna denied coverage for my son's ABA, for the first of several times. Each of these denials ignores my son's progress and continuing treatment requirement, and ignores the discharge criteria and fade plan provided in his provider's reports. Instead Cigna denied medical necessity because responsibility for ongoing intervention had not been turned over to his family.

By this reasoning it is hard to see how Cigna's concept of medical necessity is connected to the messy reality of the individual insured. As autism professionals, you know all the usual reasons why ABA programs end: **The child is not progressing, the family and treatment team disagree, or the family is unable or unwilling to continue meeting the demands of ABA.** But what if none of the usual reasons come to pass quickly enough to satisfy the managed care folks? How can they deny medical necessity for a patient who continues to flourish in the only scientifically validated therapy for his condition, racking up steady solid progress, with every appropriate support from his family and provider? **My son has come a million miles in his therapy, but he still needs ABA to address fundamental deficits arising directly from his diagnosis of autism.** We submit regular detailed progress reports together with letters from ourselves, his primary care physician, classroom teacher, BCBA, and developmental pediatrician, all attesting to his ongoing need for ABA. How does Cigna overrule all that?

Cigna's remedy is to assert that, because our BCBA has not somehow "transitioned" the entire program and all her expertise to the family, she and we are at fault and medical necessity is not met. Cigna can thus ignore my son, and the abundance of evidence submitted on his behalf, outright; the decision is no longer about him at all. Cigna denies medical necessity because treatment has not been "transitioned" to "the parents and the community"—and remember, "transition" is Cigna's euphemism for termination. That is bare-knuckled health care rationing swaddled in soothing vocabulary words. Cigna's own case management notes reflect months of browbeating of our BCBA (by a "peer" who is neither a BCBA nor an expert in autism) to discharge my son from treatment, against her clinical recommendation and her professional responsibility to him. **When she did not "transition" him fast enough,**

Cigna terminated funding. It's a Procrustean bed: If the child does poorly, cut him off; if the child does well, cut him off anyway and blame it on the BCBA and family. This is not precisely the old refrigerator-mother slur that Mom caused the autism, but it's painfully close: The autism isn't fixed because Mom is failing to fix it, so why bother with this kid?

The phrase "transition treatment to parents" in the context of autism treatment appears only once on the entire Internet: in Cigna Behavioral Health's medical necessity criteria for ABA. As far as I know, no other provider or insurer holds that expectation for any treatment of any condition. That's good news for the autism community, because the policy implications of "Get your mom to treat you" are insidious. In the era of the Affordable Care Act, the many forms of expensive professional treatment required by children with autism are increasingly funded by health insurance, or else not funded at all. That's what insurance is for: The expensive care required by the unlucky few is amortized over the many. If insurers can unload responsibility for ABA and other medically necessary professional treatments onto the families of those unlucky few, our community and your livelihood are threatened.

After Cigna's initial denial, it took me 18 months, many spurious denials, and thousands of dollars in legal fees to get Cigna to put my son's file in front of someone—anyone—with any working knowledge of ABA. Through an appeal, this other anonymous doctor working for an independent review organization evaluated my son's case and found clearly and quickly that my son's case met Cigna's medical necessity criteria because he continued to benefit from treatment in core areas of autism.

In conclusion, it seems particularly bizarre that Drs. Papatola and Lustig touted their notion of medical necessity in the journal *Behavior Analysis in Practice*. I have never heard of any other scientists comparing an entire profession to riding a bike. As an autism mom I implore your readers: Keep advocating for your patients' needs as they exist in clinical reality. Do not be swayed by misinformation put out (under guise of "collegiality") by insurance company employees who have little or no expertise in helping people with autism. Cigna may treat ABA as a glorified babysitting service; autism parents know better.

Compliance with Ethical Standards

Conflict of Interest I declare that I have no conflict of interest.

Informed Consent My son and some of his otherwise-protected health information are referenced; as his mother and legal conservator I give informed consent to their publication for this purpose.

At this writing in April 2018, Cigna has removed "transition treatment to parents" from its updated Criteria of Medical Necessity.