



## PERSPECTIVE

# Controversy: the creation of diagnostic “haves” and “have-nots,” an inadvertent cause of healthcare disparities among neurodevelopmental disabilities

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*Case vignette: “Jason” is an 11-year-old boy, whose mother brings him in for a comprehensive Developmental-Behavioral Pediatrics consultation, with question of whether he might have Autism Spectrum Disorder (ASD). Primary behavioral concerns are that he has frequent explosive behaviors, during which he physically attacks his mother and younger sister, and also bangs his own head, very hard, leaving bruises. Developmental history is significant for history of speech/language delays, delayed toilet training, long-standing and persistent academic difficulties, and significant social difficulties. Jason’s therapist referred Jason with reported goal of obtaining medical diagnosis of Autism, to access more school support, Applied Behavioral Analysis (ABA) services and Developmental Disability Services (DDS), to access much-needed respite supports.*

*Mom tearfully relates that she is worried that if they don’t access respite services soon, Jason’s disruptive behaviors will lead to out-of-home placement. On further exploration of social history, mother reports that Jason witnessed domestic violence between his parents, from birth until age 5, when both parents enrolled in drug rehabilitation and family therapy. Mom reports that both parents have been clean and sober the last 6 years and there is no ongoing domestic violence.*

*On structured observation, using Autism Diagnostic Observation Schedule, Jason exhibits typical eye contact, social referencing, joint focus of attention, shared enjoyment, bids for attention, response to overture, use of normal prosody and vernacular, immature vocabulary and insight. Cognitive testing finds mild impairment in all sub-scales and overall, and on adaptive questionnaire, mom endorses adaptive impairment in all domains. In conclusion, Jason receives a diagnosis of Intellectual Disability (ID), Trauma and Stressor Related Disorder (TSRD), and rule-outs of Intermittent Explosive Disorder vs primary Mood Disorder.*

*Mother receives this news tearfully, and somewhat angrily, noting that without an ASD diagnosis, she fears Jason will be unable to access needed supports and services, and says that after waiting so many months for DBP consultation, she had anticipated an ASD diagnosis. When it was explained to mom that he can access ABA with the indication of self-injurious behavior and receive respite supports and increased educational services with an ID diagnosis, mom is somewhat reassured. However, the ABA referral is rejected by ABA agencies without ASD diagnosis, even though that decision violates state ABA law and is not supported by available evidence. Furthermore, county DDS rejects the referral, with the argument that Jason’s adaptive impairment may be due to trauma. After these unfortunate examples of unsuccessful advocacy for family, a local*

*psychiatrist diagnoses ASD. With ASD diagnosis, Jason is able to access ABA and DDS. Thus, yet another child who does not have ASD now has that diagnosis, with significant buy-in from family, thus contributing yet another fictitious ASD diagnosis to the “autism epidemic”.*

This vignette illustrates the now ubiquitous phenomenon in the US healthcare system of families seeking ASD diagnoses to obtain needed services and of developmental and behavioral diagnosticians favoring ASD diagnoses to assist children and families to access services, even when available evidence does not support an ASD diagnosis.<sup>1</sup> Diagnostic confusion about ASD and other diagnoses, including TSRD, goes back to the origins of our understandings of these syndromes.<sup>2</sup> ASD was initially understood to be a TSRD; the “Refrigerator Mom” hypothesis was the dominant framework of understanding ASD for a generation after ASD was first codified.<sup>3</sup> By blaming ASD on parents, it prevented the diagnosis from being used by compassionate diagnosticians, thus causing ASD to be a rare curiosity for a generation.<sup>4</sup> It prevented families from advocating for therapies, services, research, and so on.<sup>4</sup> It took a parent rebellion to discredit the Refrigerator Mom hypothesis, and this led to a rather adversarial relationship between parent support groups and professionals to this day.<sup>5</sup> Unfortunately, this has empowered harmful anti-establishment movements such as the anti-vaccine movement, as well as an over-emphasis in popular media on ineffective and sometimes dangerous biomedical interventions.<sup>5</sup> This original error continues to adversely impact the diagnostician–parent relationship and to undermine the authority of “ASD experts” in the eyes of families.

Fortunately, now ASD is understood to be a common condition, deserving of substantial funding for services, supports, and research.<sup>6</sup> Regrettably, in the process of successfully increasing ASD awareness, we have inadvertently created diagnostic “haves” and “have-nots”.<sup>7</sup> By allocating funds to ASD and continuing to neglect the needs of other vulnerable children, such as children with ID and children who have experienced trauma and abuse (TSRD), we have predictably but unfortunately created an epidemic of the diagnostic “haves,” such as ASD, while continuing to neglect the needs of have-nots (such as TSRD, ID, etc.)<sup>1</sup> We have successfully increased ASD awareness and have created a mandate for primary care physicians to screen for ASD, which has been a public health success.<sup>7</sup> However, we have failed to put adequate funding into diagnostic capacity, causing a bottleneck for diagnostic assessments, greatly delaying access to valuable

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services, increasing stress on families, and continuing to strain the diagnostician–parent relationship.<sup>8</sup> We have successfully communicated that obtaining an ASD label can facilitate access of valuable services, such as DDS supports, educational services, and ABA, but have failed to fund adequately such treatment and support services.<sup>9</sup> Simultaneously, we have failed to fund services for the have-not conditions, for example, ID and TSRD, with the result that such diagnoses, already stigmatized, are even more under-utilized, unpalatable to parents, and causing even more of these children to be referred for ASD assessments, thus further congesting the ASD diagnostic pipeline.<sup>10</sup>

It must be emphasized that the problem is clearly not that we allocate too many resources to research, diagnostic, and treatment services, including educational services, for individuals with ASD. Quite the contrary, the problem is not that ASD is over-funded. Indeed, given persistent severe inadequacies in healthcare, social services, and educational services experienced by individuals with ASD and their families, it is clear that we must allocate yet more resources to ASD to better address persistent unmet needs.<sup>9</sup> However, the current approach—of targeting funds to the ASD label and continuing to engage in such relative neglect of TSRD and ID—has resulted in diagnostic bias, diagnostic inaccuracy, and misplaced interventions. So, the problem is not that ASD is over-funded, but rather that, relatively speaking, other conditions are under-recognized, under-researched, and under-treated.<sup>10</sup>

So, what are the solutions to these current problems? First, prevention is more efficient and effective than cure. At this time, we continue to pursue or to tolerate policies that contribute to actually contribute to the epidemic of TSRDs.<sup>11</sup> For example, we tolerate child poverty, hunger, homelessness, and exposure to drugs, other toxins, and violence. Tragically, the government is even a direct agent of trauma, such as at our southern border, where we engage in the jailing of children, separation of children from parents, and in our inner cities, where we continue to apply unequal justice based on socioeconomic status.<sup>12</sup> Obviously, we must reverse policies that actually create emotional disorders in our children and youth.

Second, we should update policy and service allocation to be congruent with current science. Specifically, research clearly shows that trauma induces changes in the functioning of the brain.<sup>13</sup> Thus, it is generally acknowledged in the scientific community that TSRDs are neurodevelopmental disabilities. Therefore, it is arbitrary to allocate services to NDDs and fail to allocate services to TSRDs. However, the policy has not yet caught up with the state of our understanding of development.<sup>14</sup> A diagnostic label—for example, ASD—does not indicate the level of function or need for supports.<sup>15</sup> We should allocate services based on function and need rather than based on the diagnostic label.<sup>16</sup> This would lead to the amelioration of diagnostic haves and have-nots, would help to reduce the creation of fictitious epidemics, and would assist in allocation of supports and therapies more appropriately, to the people who actually need it.

To allocate increased supports and services to a broader range of diagnostic categories would cost more, of course. To address this concern, it should be noted that investment in services for children tends to provide a robust return. Increased educational, healthcare, and social services for children saves money in the long run by improving productivity, reducing costs to the adult justice system, adult social services, and so on.<sup>17</sup> Also, more funds would be available for actual treatment if we took more care to insist that the taking of healthcare profits are contingent on the provision of adequate supports. For example, even public insurance (Medicaid) administrative units are currently taking huge profits with negligible accountability for ensuring the provision of adequate developmental and behavioral services for children.<sup>18</sup>

In summary, we must pursue policies that reduce chronic, toxic stress rather than continuing to exacerbate trauma in children. Additionally, we should allocate services based on functional challenges, not on diagnostic labels. Finally, we must no longer tolerate the status quo, in which we allow public and private insurance entities to continue to profit while failing to address the fact that children with special healthcare needs to continue to suffer exceedingly long wait lists for developmental and behavioral diagnostic and therapy services.

## AUTHOR CONTRIBUTIONS

R.P. is the sole author of this manuscript; he conceptualized and wrote the manuscript.

## ADDITIONAL INFORMATION

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