
27 Turning the Tables

Autism Shows the Social Deficit of Our Society

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The autistic condition, as currently defined by observation and dependent on a priori defined notions of social appropriateness, has gained prevalence of epidemic proportions worldwide. In the United States, the systems that diagnose and treat the condition follow a clinical model primarily based on a psychological or psychiatric construct. Such an approach leaves out bodily physiology and its sensory consequences in favor of descriptions and interpretations of observational data gathered by hand without proper scientific rigor. The clinical model thus constructed serves a fast-pace system to provide recommendations for treatment that directly impact the lives of the affected individuals and their core caregiver family unit, but fails to embrace them as active members of society at large. While limiting the potential contributions of the autistic person to our society, the current clinical model is also interfering with the scientific model and its progress, which has considerably stalled. This chapter exposes some of the contemporary issues surrounding the complex relationships between society at large and the autistic population in the context of a psychological or psychiatric model that is not working.

It's not science ... it's politics and economics; that's what psychiatry is: politics and economics.

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AUTISM: THE CURRENT DEFINITION

Defined as a deficit of social interactions, characterized by lack of communication and the presence of repetitive, restrictive behaviors (American Psychiatric Association 2013), autism spectrum disorders (ASDs) is now one of the neurodevelopmental disorders with higher prevalence in the United States. Soon enough, the so-called epidemic proportion of affected children will turn into affected young adults.

Indeed, the latest report on estimated prevalence of ASD based on 2014 data was 2.24%, “a significant increase from the estimated annualized prevalence of 1.25% based on 2011–2013 data” (Zablotsky et al. 2015a). How can we as scientists help address this societal problem?

The social definition of this neurodevelopmental problem affords more than one level of description and interaction. At present, the burden is placed on the affected person. One gets the feeling that “*they* are the ones with a problem: We ought to change *them* to conform to us” (Odom 2016). In this process, the majority of society may fall into one of several self-evident categories: mere spectators of a problem that has been portrayed in science as one of the biggest contemporary puzzles of the human brain with no foreseen solution in the near future, actuators on the problem to “cure” it or “reshape” it at all cost, people who care about the individual with autism and want to desperately help, and self-advocates who have somehow found a voice. However, there is an additional stand-alone category: those who profit or want to profit from this problem. These individuals inevitably drive the focus of other groups and society at large.

First, let us examine this problem using the lens of a researcher who tends to think outside of the box: An expectation comes from the systematic or frequent occurrence of events that surface so often and with such regularities that they reach statistical power of the kind that one can predict an outcome probabilistically and confirm it most of the time with high certainty. An oddity or unexpected outcome that does not conform to the preset expectation (e.g., a social norm) is indeed worrisome—particularly if the occurrence is so randomly heterogeneous that there is no pattern to classify it into something previously known. We do not know how to cope with it, so in a way, we lose our control over the situation. Let us then consider the implausible scenario that one morning we wake up only to find out that we lack total control over social situations and that, in the presence of such lack of control, we have acquired a social deficit ourselves: we have been labeled “autistic.” As such, I wonder how we, as a society, should be treated. Should we all be reshaped through conditioning-based treatments? Should we all be medicated to eliminate this autistic condition? Should we all be deprived of our free will? And if so, who may be given the credentials to do this to us? Who will be authorized to treat us and reshape our behaviors to conform to expectations? What laws would protect us? And who will be dictating those laws? Scary, isn’t it? The mere thought of it should make you wonder how a child with ASD, subject to all the above, feels about the rest of us.

Indeed, to have a true appreciation, we must flip roles and rethink this problem from the perspective of the affected child, that is, the human being that we (perhaps unknowingly) have robbed of any chance to be part of our “expected” social world. Let us have a look at the side of autism that very few of us in science come to think about.

TWO DIFFERENT GOALS: VERY DIFFERENT OUTCOMES

The main focus of psychiatry and clinical psychology is patient care. As such, these fields operate at a faster pace than basic scientific research. They must address real mental issues at a large scale and provide fast solutions to imminent crises. In these fields, time is of the essence. The basic scientific pursuit stands in stark contrast to this fast pace, as it requires careful testing and retesting of hypotheses through empirical verification and validation. The tenets, goals, and time frames of the scientific community are different from those of these two clinical fields. *Why is it then that these clinical fields drive our scientific quest today in areas concerning disorders of the nervous systems, such as ASDs?*

The nature of the clinical endeavor, its necessary accelerated pace, and the immediate need for treatment require a fast system of data gathering. As a result of these constraints, clinical practice gathers data through very subjective means. These include observation and interpretation of behavior accompanied by hand coding based on discrete numerical scales. These scales reflect a range of possible interpretations of what the clinician observes the patient doing in response to a given questionnaire or task. Additional metrics are often based on self-assessment, assessments by caregivers,

or combinations of those and the clinician's assessment. This form of data gathering fits the clinical needs, but leaves out, by necessity, the vital detailed-level information required by scientists investigating the disorders of the nervous systems.

The naked eye has limited capacity for the conscious processing of visual information. While behaviors occur along a continuum, the information that is coded through such clinical reports (that which reaches consciousness) is intermittent, subjective, and lacking the precision to capture aspects of behaviors that occur largely beneath awareness. These include involuntary micromotions of the face and body that are much too fast or too subtle to be detected by the eye, as well as other physiological signals underlying behavior that are reachable only through instrumentation. Thus, although the scientists working within these clinical fields are forced to use the clinical data to validate their instrumentation-based data, the two are utterly dissimilar in more than one fundamental way.

First, owing to its subjective nature, the clinical data are difficult to reproduce with high reliability. For instance, while completing Autism Diagnostic Observation Schedule 2 (ADOS-2) training, I noted with dismay that it took nearly 30 minutes to reach a general consensus across 20 people (clinicians and researchers) on whether a child displayed behaviors indicative of anxiety. During this discussion, individuals drew on their own clinical perspective, leading to a variety of other possible outcomes being raised, illustrating the subjectivity of such metrics. Moreover, these assertions were based on discrete behavioral interpretation, not a continuous real-number-based scale reflecting physiological states in a standardized way.

Second, the fact that clinicians are trained to look for certain traits and expect certain outcomes may inherently skew data interpretation and thus scores. If the instrumentation-based data that the scientist gathers along a continuum uncover aspects of the phenomena that the clinical data failed to capture, there will be poor correspondence between the observed description of the behavior and the actual physical measurement of it. Therefore, we are left with an incomplete picture of the phenomena if we rely only on one side of the coin. However, if we use both approaches, it is vital that we maintain a level of independence between these two forms of data gathering and interpretation. Failure to do so will result in one form of data collection confounding the other, and vice versa, and thus continue to skew our inquiry, leading to the circular arguments we often have today.

Third, the above issues with clinical, observational data prevent blind reproduction of results across different labs—an important step of the scientific method to provide a natural system of checks and balances. Science relies on the openness of the data sharing and reproducibility of their results. Without that, there is no progress in science. Given the subjective nature of clinically derived data, it is difficult to ensure blind reproduction of data.

Lastly, external supervision by experts in different fields is commonplace within the scientific arenas that investigate the brain and body interrelations. This interdisciplinary endeavor contributes to the progress of the scientific inquiry, and the rigor of the scientific method. Yet, within the clinical arena a neutral observer from another field would be considered an intruder, and due to patient-practitioner confidentiality and privacy issues, the scientific model of external supervision is not possible.

The data gathering of the clinical practice is also subject to the flow of interpersonal relations, which also has the potential to bias the data-gathering process. The scientific counterpart of gathering data with instrumentation and anonymity is impervious to other social nuances. To the instrument registering the data, the subject's data are just streams of numbers. To the scientist analyzing it, the data are just that. There are no strings attached. *Why is it then that the scientist is forced to use the clinical data necessarily gathered under such confounding terms?*

There is no immediate correspondence between the goals of the clinical and scientific endeavors. Both branches of the medical field ultimately aim to cure disease in the long run, but in the short run, the goals of patient care and those of the scientific inquiry are much too different to accommodate each other. If science were to impose its standards on clinical practices, clinicians simply could not run their operation. Patients would not receive the care that they need when they need it, and

clinical practices would be stalled. However, this is exactly what is happening today in the scientific pursue of neurodevelopmental disorders, such as ASDs. We scientists, forced to use the data gathered under the clinical model, are stalled. Our progress is stalled because our model is fundamentally different from the clinical model. The clinical data that we are forced to use are incomplete, skewed, plagued with confirmation bias, and gathered in ways that are difficult to reproduce. Using these data is not only interfering with scientific progress in our inquiry but also extremely costly. Science lacks the budget to run this operation.

FOLLOW THE MONEY

In psychiatry, there are well-known financial ties between the pharmaceutical companies and the makers of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association 2013), dictating the diagnoses (Cosgrove et al. 2006, 2009a, 2009b, 2014a, 2014b; Cosgrove and Krimsky 2012). There are also conflicts of interests between the companies that make psychological testing tools and their creators in clinical psychology. Specifically, their creators receive royalties from tests conducted in such studies (Hus et al. 2014). Disclosing financial ties between psychiatry and Big Pharma or donating royalties to charity does not change the fact that the system is ill-conceived and deeply corrupted (Cosgrove and Wheeler 2013). Practitioners and researchers in these fields may have the best intentions to help the affected person, yet they have no control over the consequences of their actions or decisions. The ways in which the system is inherently structured give rise to hidden variables researchers and practitioners are not even aware of, so they cannot factor these into their decision-making process. As an example, in the cases of neurodevelopmental disorders, those administering the tests are a vital component of the interactions with the child under evaluation, yet there is no built-in supervision or proper assessment in the tests to determine the types of biases the examiners may introduce. For instance, during the administration of the ADOS-2—used to diagnose ASD—the examiner creates a controlled social environment for dyadic interaction with an examinee. However, despite the fact that the clinician administering the test is paid to do so, there is no control for any biases or inherent variability of the examiner’s performance (see Chapter 7; Whyatt et al. 2015; Whyatt and Torres 2017). Moreover, in addition to being used for diagnostic and clinical purposes, these tools are often an integral piece of research. In particular, given the complex and stringent research standards imposed in the scientific community, research teams must first confirm diagnosis—for instance, of ASD—using clinical assessment tools. In this regard, the clinical method, designed with different goals and under different standards than the scientific method, is leading the basic scientific inquiry in ASD.

The financial burden on the scientific community is also felt. A number of such clinical tests have dual formats, that is, clinical versus research grade. This duality leads to inflation of the profits for the administration of the test, but also results in higher costs to do the science. Interestingly, the training procedures and rules for these tools are often more complex and demanding for the research-grade test—rather than the clinical test—which in and of itself questions the clinical world’s approach to psychiatry.

SOME UNFORESEEN CONSEQUENCES OF THE FINANCIAL CONFLICTS OF INTEREST PLAGUING AUTISM DIAGNOSES AND TREATMENTS

Despite the known financial conflicts of interest, despite the lack of objective measures in their testing platforms, and despite the lack of external supervision and the condition of near impunity on the outcome of treatments, the fields of both psychiatry and clinical psychology exert an enormous power over the scientific community. For example, in the case of ASD, no research can get published unless the clinical scores are reported and correlated with the objective measures from instrumentation

that scientists perform. Due to the aforementioned clinical model, the cost of a basic science research project with high statistical power is generally prohibitive. The scientific progress concerning neurodevelopmental research has stalled because of this circularity, where the errors and pitfalls of test scores and their limited or inconsistent statistics are unavoidably inserted into any empirical study of autism.

Mathematically, it is also incorrect to conduct correlations between these two disparate scales (discrete-linear clinical and continuous-nonlinear-dynamic physical). The discrete makeup of clinical scales generated by subjective methods assumes a normal distribution. This assumption tends to smooth out as noise the inherent fluctuations in data that come from a coping biological system, which is daily and rapidly changing during development. In the face of dynamic physical changes, the clinical scales are inherently static as they rely on absolute rather than incremental values (i.e., in the few cases where they are systematically and longitudinally used, they do not consider derivatives from visit to visit, reflecting change as the person ages).

The nervous systems of a child are changing at accelerated rates, following a rather nonlinear dynamic process with multiplicative stochastic signatures of variability (Torres et al. 2013a, 2016)—these cannot be empirically evaluated using clinical scales. It is thus inappropriate to correlate discrete, static, linearly conceived clinical scales—conceptualized under assumptions of additive statistics—with the continuous biological signals that are objectively captured from the physical body and/or brain of the person. We scientists are simply being forced to compare “apples and broccoli” at an extremely high cost.

DISCRETE SUBJECTIVE SCALES CANNOT CAPTURE ADAPTIVE CHANGE

Besides their pervasive influence on basic scientific research, psychiatry and clinical psychology hold an enormous power over the population at large. Society at large is impacted by their practices in nonobvious ways. One of these ways concerns the affected person and the supportive family unit. The disorder type that these fields dictate determines not only the kind of treatment the affected person may receive, but also the type of coverage the child’s family may ultimately afford for such treatments. Since discrete scales are static, they cannot capture the types of nonlinear dynamic and stochastic changes of the nervous systems of the child under therapy. Such scales are unable to provide objective outcome measures reflecting underlying change in the nervous systems to assess the intervention’s effectiveness, or to help insurance companies longitudinally assess the balance between benefits and risks of a given therapy.

For example, a child with ASD may need occupational therapy (OT) with a focus on sensory-motor issues, but this is not covered by insurance companies (Thomas et al. 2007, 2012; Benevides et al. 2015). Despite evidence of their disruption (Mostofsky et al. 2000; Minshew et al. 2004; Takarae et al. 2004; Gidley Larson et al. 2008; Haswell et al. 2009; Fournier et al. 2010; Torres 2012; Torres and Donnellan 2012; Brincker and Torres 2013; Mosconi et al. 2013; Torres et al. 2013a, 2016), sensory-motor issues are not considered part of the disorder by these two disciplines. In particular, any reference to sensory-motor issues is indirect—it occurs at a descriptive level in connection with motor use, for example, gestures, sensory aversions or interests, and repetitive or restricted behaviors. These difficulties are never examined in relation to the underlying physiological signatures from neurological interactions between the central (CNS) and the peripheral (PNS) nervous systems. Yet, the emergence of sensory-motor difficulties is a repercussion of physiological functioning. It is as though sensory and motor nerves transporting the signals along the nervous systems and enabling communication across the various structures for autonomic, automatic, and voluntary control did not exist within the framework of clinical metrics. Indeed, the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) criteria ignore the neuroanatomical and neurophysiological underpinnings of human behavior, which is reflected as well in their exclusion in diagnostic tools and tests, such as the ADOS (Lord et al. 2000). This conceptualization of ASD as a high-level

description of subjective quantification of observed behaviors further drives the recommendations of coverage for therapies. As such, clinical scales and interpretations restrict the types of treatments a given family will have access to.

Without access to insurance coverage for treatments of sensory-motor disorders in neurodevelopment, the large majority of affected children grow up without sensory-motor-driven interventions. The child with autism will receive what is available through state programs after school age (Liptak et al. 2008; Lubetsky et al. 2014). A common intervention in this regard is applied behavioral analysis (ABA). Yet, that intervention was not designed to address issues concerning sensory-motor disturbances of the nervous system of the child. In fact, the very therapy renders some “behaviors” inappropriate or nonconforming with their protocols of what is appropriate. As such, they may “extinguish” those behaviors through punishment schedules. This is the case even when such seemingly odd behaviors may serve a purpose, for example, to comfort the child in the presence of sensory-motor issues unseen by the naked eye of the clinician. Under such uncertain conditions and lack of objective, physical measurements, it is possible that despite meaning well, the clinician’s approach may in fact be harmful to the child.

Consider for a moment the excess of uncertainty that motor noise and randomness (Brincker and Torres 2013; Torres et al. 2013a) bring to the child’s nervous system, and then amplify this with the type of uncertainty that prompting alone must bring to that child. Indeed, seasoned ABA therapists that have a tremendous interest in helping the children with ASD have privately communicated that anxiety, stress, and tantrums are commonplace during ABA sessions. We do not know the underlying physiological signatures of these manifestations, or how they impact the nervous systems of the developing child subject to such behavioral modifying therapies. When questioning some practitioners about this, the response invariably has been, “It’s autism.” Circular, isn’t it? It is as circular as is the clinical criteria leading the scientific quest.

UNCERTAIN OUTCOMES OF PSYCHOTROPIC MEDICATIONS AND BEHAVIORAL MODIFICATIONS

An important aspect of neurodevelopmental disorders treated by psychiatrists and clinical psychologists is the profound impact that these treatments are bound to have in a developing human. As explained above, the manifestations of neurodevelopmental disorders coupled with the reliance on a discrete description or interpretation of symptomatic behaviors fails to provide enough information to make truly informed decisions on the course of treatment. Specifically, these discrete metrics fail to capture adaptive change—particularly at a time when physical growth and the development of the neural control of movement are changing at accelerated (nonlinear) rates (Kuczmarski et al. 2000, 2002). These pitfalls lead to an absence of proper methods to track the effectiveness of behavioral interventions, including as well the assessment of the risks of psychotropic drugs on the immature nervous system of an infant or a young child.

Pharmaceutical companies and the American Psychiatric Association are now by law forced to disclose their financial ties (by the health care overhaul legislation [Greenberg 2003]). Yet, disclosure is not enough to show the public the profound side effects of these drugs, which were not designed for children in the first place. Indeed, these drugs have measurable deleterious effects on the child’s nervous systems (Torres and Denisova 2016). These effects are not considered or noticed by clinicians due to the inherent limitations of clinical tools, potentially compounded by profound financial ties that the clinical fields are known to have with pharmaceutical companies (Cosgrove et al. 2014b).

As in the case of psychotropic drugs, the behavioral modifying interventions imposed on the child are thought to have an impact on the child’s development. As with psychotropic drugs, there is a paucity of objective methods to inform clinicians of the changes that the treatments exert on the child’s nervous systems. As such, practitioners in those fields provide, rather blindly, a “one-size-fits-all” approach to disorders that are, by the very nature of the ways in which the disorders are defined,

very heterogeneous. They are called “disorders on a spectrum,” and yet, by default, early intervention programs given to each child with a diagnosis of a neurodevelopmental disorder provide similar treatment or behavioral intervention as any other child on that spectrum.

POLITICS AND ECONOMICS

These financial ties have implications on the lines of available therapies. In the United States, the type of coverage therapies received depends on the politics that affect the decision making of the judiciary branch of the government. As such, if a strong financial force backs a certain intervention, it is likely that taxpayers will end up covering those expenses. Yet, taxpayers are not well informed of the science behind such interventions. In a democratic system, being well informed is vital to decide and vote on lawmaking. That process is critical, as it has direct implications on the lives of those affected (i.e., the child and the family). Furthermore, because of the lack of information, ordinary citizens may not immediately foresee possible implications the legislation might have on other aspects of the problem that may affect their own lives, for example, have an impact on the educational systems or the resources needed for other areas of patient care.

THE PARENTS’ IMPOSSIBLE ROAD TO DIVERSIFIED TREATMENTS

The processes involving treatment recommendation and the corresponding legislation of treatment coverage by insurance companies are very complex. Their rulings inevitably constrain the options available to the affected families. As a consequence, the family is left with no path to diversify treatments and increase the likelihood of improving the child’s quality of life. A case in point is the intensive use of ABA nationwide. As explained before, this type of intervention was not designed to address the types of sensory-motor issues underlying the behaviors that this method attempts to modify. Indeed, a range of neurophysiological issues that have been scientifically established in children with ASD (Torres 2013; Torres et al. 2013a, 2013b, 2013c, 2016) are not factored into this intervention.

For instance, ABA is thought to improve structuring the child’s actions. The therapy is based on animal conditioning models with stimulus–response associations made through schedules of reward and punishment (Hergenhahn 1973; Matson 2009; Raber 2011). Unfortunately, such methods, which rely on explicit instructions and external prompting, often rob the child of the opportunity to spontaneously self-discover cause and effect on their own (Torres et al. 2013d). This process is fundamental to engage more primitive structures of the autonomic nervous systems and promote a natural bridge between high-level CNS structures and low-level PNS structures that appear earlier in evolution than those in the neocortex.

Neurodevelopment occurs according to a phylogenetic order in the structures of the nervous systems. Within hours of life, the bodily rhythms of the newborn entrain with those of adult speech (Condon and Sander 1974). Likewise, rhythmic patterns of respiration, feeding (sucking), and cooing develop rapidly, contributing to the baby’s survival (Barlow and Estep 2006). These motoric rhythms are controlled from the onset of life by primitive structures of the brainstem and central pattern generators developing in the spinal cord. They mature and allow survival before the baby can think in the abstract and make decisions. This level of bottom-up control (from autonomic to voluntary) scaffolds the gradual emergence of volitional control. Indeed, top-down operations, such as those driven by prompting, require the neocortical control and coordination of voluntary, automatic, and autonomic layers of the nervous systems, yet these functions develop from the bottom up, and these lower levels of control should not be assumed a priori before any type of intervention begins.

If the scaffolding of peripheral and subcortical structures of the nervous systems has a glitch during early neurodevelopment, it may be necessary to step back and “awaken,” from the bottom up, those structures that evolutionarily mature earlier to enable reflexes, central pattern generators, and

spontaneous motions to facilitate self-exploration and self-discovery. Yet, ABA is unable to accomplish such objective profiling and targeted intervention due to the very nature of the therapy. This therapy is based on extrinsic prompting, instructed from the top down using external reward-based associations under the assumption that the child's mental intentions already match the volitional control of the physical body. That matching between mental intention and physical action is the very end product of a maturation process that followed a typical path, but ASD is the by-product of a process that followed an atypical neurodevelopmental path. In this sense, therapeutic interventions such as ABA seem backward, failing to build on core principles of neurodevelopment.

Furthermore, in our own experience many of the ABA programs that are claimed to be successful in improving the child's performance (verbal or otherwise) filter out of admission children that are not likely to succeed. This practice was evident even in the very early work by Lovaas (1987) reported in the ABA literature (see the "Methods" section: "high agreement was not reached for subjects who scored *within the profoundly retarded range on intellectual functioning (PMA < 11 months); these subjects were excluded from the study*"). Such a screening method underscores the need for a broader and more diversified approach to interventions, so as to help those nonverbal children in the spectrum that are now underserved by the public school system. Their parents may gain access to special education and other resources through a rather expensive and tenuous litigation path that only a few can afford. That path is, however, not obvious to most. In fact, we discovered this through a long interview process sponsored by funds from the Innovative-Corps Program of the National Science Foundation, whereby 117 individuals in the ecosystem of autism were interviewed (including lawyers, parents, counseling services across the nation, board-certified behavior analysts (BCBAs), ABA schools, therapists from diverse areas such as physical and occupational, and insurance companies).

The ABA schools that I have personally visited in the New Jersey area (e.g., the Rutgers Douglass Developmental Disability Center and the Princeton Child Development Institute—quite successful at what they do, I must point out) already include some elements of OT and physical therapy (PT) in their practices. Yet, officially this is not recognized by any BCBA curricula. The curricula do not call either for experts from those fields or from the fields of sensory-motor neuroscience. Including sensory-motor physiology as part of the BCBA curricular training would help enrich their knowledge on the neurophysiology and neuroanatomy of the developing child's nervous systems.

Large bodies of scientific evidence from the fields of developmental neuroscience are not being actively utilized in the ABA model, a model that is based on the psychological construct that behavior—to be socially acceptable—must look a certain way. Without physically measuring the consequences of intervening in a coping nervous system with complex evolving physiology, this type of practice—necessarily skewed by one's interpretation and opinion of the observed responses of the child and blind to the nervous systems' physiological responses—can have very uncertain outcomes and unknown consequences in the long run. What is rather certain is that such practices are bound to target a very narrow aspect of the individual's existence and, as such, be severely incomplete.

Classical ABA seems to enhance a different skill set than that necessary to achieve functional goals and bodily awareness. As necessary as the skills that ABA teaches in the classroom may be, they do not necessarily transfer to other domains (Baer and Wolf 1987). This is particularly the case in activities of daily living, as well as those involving navigation and basic social exchange outside the school settings. Even simple daily tasks, such as taking a shower, tying one's shoes, or buttoning down a shirt, require other skills within the realm of visuomotor control, eye-hand coordination, sensory-motor integration, and bodily sensing (proper feedback from self-generated motions), all of which require an intrinsic element of autonomic control, self-initiation and stopping, and autonomous sensory-motor sequencing. Specific forms of neurological music therapy (NMT) (Thaut et al. 2014), OT, and PT interventions focusing on sensory-motor integration

can enhance these important components that are so necessary to scaffold all naturalistic behaviors. However, unlike ABA, these therapies are not covered by insurance, or offered at the public schools (Zablotsky et al. 2015b). At present, they are very costly and only affordable by a very small segment of the very large number of individuals affected in the United States (Autism et al. 2012; Perou et al. 2013). It would be very interesting to know how the rest of the world is doing this.

SOCIAL DEFICIT OF OUR SOCIETY

One of the most poignant aspects of our research involving children on the spectrum of neurodevelopmental disorders like ASD is their enormous efforts to “fit in”; upon their exhausting and costly therapies (for the few that can afford them), the child might make it to mainstream classrooms in regular schools. Although a triumph for the child, the family, and all those involved (including devoted ABA therapists, occupational therapists, physical therapists, and a speech therapist), the large majority of these children are bullied, sometimes beaten up so badly that they regress considerably (see Chapter 26). They are generally evaded and dismissed by their peers (Zablotsky et al. 2014). The lack of awareness and education on the true physiological difficulties that underlie the observational diagnosis and treatments of autism prevents society from truly recognizing the nature of the struggles of the affected individuals and from assuming full responsibility to support this population. The perception created by the DSM and the ADOS criteria—portraying autism as a mental condition or a social deficit, often interpreted and perceived as a deliberate social withdrawal—does not help. The treatments geared to reshaping “socially unacceptable behaviors” without supporting the sensory-motor needs of the person are not helping the situation either. Rather, all of it exacerbates the stigmatization of the affected individual and leads to such a state of loneliness that only those who suffer it and those who listen to their testimony can truly come to understand it (Donnellan et al. 2012; Robledo et al. 2012; Amos 2013; Savarese 2013).

The influences that psychiatry and clinical psychology have on the legislation and finances behind neurodevelopmental disorders bring high uncertainties to the future life of any affected child and his or her family. First, due to the high costs associated with diagnosis and treatment during the early years of life, there is a paucity of programs implemented to address the disorders as the person evolves with aging. As such, there is no system in place to support the life of the person as an independent adult. Second, the development of the sensory-motor systems required for the acquisition of autonomy, self-control, and agency is not being promoted by any of the diagnoses and treatments currently available. In fact, the sensory-motor systems are negatively impacted by the deleterious side effects of psychotropic medications (Torres and Denisova 2016). Without this basic physiological foundation to scaffold self-autonomy and ultimately free will, there is little chance to welcome and foster the affected individual as an active, contributing member of our society. Thus, the forces at work to diagnose, treat, legislate, and finance all aspects related to neurodevelopmental disorders on a spectrum have yet to consider those disorders along the continuum of the human life span. The consequences of errors in their handling of the situation are merely starting to show. To this day, we do not know what the present treatments do to the brain or body of a developing child. Consequently, we do not know the resulting outcomes in the adult system. Somehow, by not properly supervising* what these fields have been doing with impunity for so long, we have failed the affected children and their families, but societally, we have actually failed ourselves. The consequences are soon to become self-evident in the nascent new generations of young and older adults on the spectrum that we, as a society, have neglected to embrace.

* Proper supervision would require multidisciplinary third-party neutral observers with no financial conflicts of interest and the integration of knowledge bases from different fields.

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