

Is Autism a ‘Public Health Crisis?’: Looking at the California Blue Ribbon Commission’s Report on Autism

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Abstract

The California Blue Ribbon Commission on Autism’s September, 2007 report identified Autism Spectrum Disorder (ASD) as a ‘public health crisis’ and ‘epidemic’ recommending an “Office of ASD” under Public Health. The Commission also said that health plans should provide “full...” services for ASD. With this, the Commission set the groundwork for a potential misdirection of public health funding, increased litigation, and unnecessary competition between families and providers of children with special needs. Though the report acknowledges that honest differences exist, it then incorrectly asserts that each has equal relevance. Rather than a ‘public health crisis,’ autism should be viewed as a crisis of instruction requiring better coordination of available services and existing knowledge with targeted support for schools, families and community providers.

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In 2005, the Legislative Blue Ribbon Commission on Autism was established based on a resolution authored by then President Pro Tem of the California Senate, Don Perata. The Commission’s goal was to directly impact the needs of children and adults with autism spectrum disorders (ASD) in the state by bringing together a group representing parents of children with autism, public and private sectors, educators, physicians, and public health officials. At its first meeting in September, 2006, three Task Forces were established. They were: (1) Early Identification & Intervention; (2) Education & Professional Development; and (3) Transitional Services & Supports.

A primary goal of the Commission was to investigate and make recommendations towards alleviating apparent gaps in the diagnosis, assessment, treatment, and support of persons with ASD and their families. In September, 2007, the Commission released its report. The report was to provide specific policy recommendations, shape and directly influence services to persons with (ASD) and their

families throughout California. The Blue Ribbon Commission’s report also closely mirrored discussions and challenges occurring around the country with regards to how services are identified and prioritized for persons with ASD and their families. The report written by the Commission on Autism is available on their website (California Blue Ribbon Commission Report on Autism, 2007).

The Commission’s work was intended to stimulate a broader discussion and review of the evolving area of assessment and intervention for persons with ASD. Thus far, that wider conversation, to include an emphasis on the report’s many strengths as well as specific concerns and challenges relevant to both California and the country, has apparently not occurred. The fact that this report represents so much time and effort in its unique attempt to directly address autism, and the lives of persons with autism, is, at the same time, both positive and unsettling.

The increased attention to autism is positive as the number of children and adults diagnosed with autism has increased exponentially in communities across California and the United States (Croen et al., 2008; Rice, 2007). Such a singular focus on the category of autism, however, risks reduced attention to why these numbers have increased as well as to children and adults with a wider range of related developmental and learning needs. Presenting autism, and needed resources, as dramatically different from other special needs may disempower professionals and non-professionals from using their training, resources, and experience to support children identified as ASD. As otherwise skilled and knowledgeable professionals, from educators to social service workers, become convinced that they are less able to support children with autism and their families based on their ostensibly distinct needs, the predicted service ‘crisis’ may become a self fulfilling prophecy¹.

Singular attention to ASD risks creating a barrier to services as it places a bubble around persons with ASD that may disconnect them from existing and directly applicable knowledge and resources. A second concern about presupposing persons with ASD to be broadly different from others with developmental and behavioral disabilities is the strong potential of stereotyping need, behavior, and individual characteristics while duplicating existing services and resources.

The Commission’s report states that a “broad array of community services available to the public and the traditional models of service available to persons with disabilities (to include through the educational system) are not designed to specifically meet the needs of those with ASD” (California Blue Ribbon Commission

Report on Autism, 2007, p. 13) without explaining how this conclusion was reached. The reality is that there are few, if any, instructional or behavioral strategies unique to children with ASD as compared to other children with and without developmental or learning challenges. Good teaching is more guided by the individual needs and learning styles of the child in combination with features of the setting and the training of the educator than the diagnostic category (Anderson & Algozzine, 2007; Sadler & Sugai, 2009; Sugai, 2000; Wehmeyer et al., 2002).

Even though children with ASD may require more explicit attention to social and expressive skill development than many of their peers, for instance, how that is taught is not typically different for children with ASD than those without (Derby et al., 1997; Earles et al., 1998). At the same time, social and expressive deficits and related behavioral needs are hardly unique to children with ASD or accountable to a unique ‘internal’ process in persons with ASD.

Studies have consistently shown that children with chronic expressive deficits are more likely than the general population to use disruptive and aggressive behaviors for communicative purposes. These same studies have demonstrated that effective intervention for communicative deficits can reduce disruptive behaviors across children with very different developmental diagnoses ranging from conduct disorders to autism (Carr & Durand, 1985; Derby et al., 1997; Gilmour et al., 2004; Horner & Day, 1991). In fact, one study (Gilmour et al., 2004) reported that a significant number of children with conduct disorders had pragmatic language impairments and other behavioral features that were similar in nature and degree to those of children with autism.

The ‘communication hypothesis’ described by Carr and Durand (1985) over twenty years ago continues to be a strong inference for the relevance of purpose, function and context over diagnostic category as the foundation for the challenging behavior often seen in children with ASD. As a result, and an example, Functional Communication Training continues to be a

¹ As a clinician and teacher with a twenty five year history of working with and supporting children and adults with autism, inclusive of 5 years in California, this author has observed multiple instances where even highly skilled educators and clinical practitioners felt unable to support a child considered to have autism before even meeting him or her based solely on the diagnostic category.

commonly used intervention and instructional model for children with ASD as well as for those across the range of developmental disabilities and special needs (Derby, et al., 1997; Winborn et al., 2002). This reality may counteract the overriding belief widely referenced in the Commission's report that presupposes a link between the behavior of children with ASD with a medical illness process like that of a cold or flu. Instead, much of the behavior evidenced by persons with ASD may be better viewed as contextually driven and functionally relevant.

From the outset, the report routinely refers to ASD as a medical 'epidemic' and a 'public health crisis' and argues for the need to create an "Office of ASD" under the auspices of the Department of Public Health. This recommendation is troubling and leads this author to wonder why California is not considering an Office of Down Syndrome, Attention Deficit Hyperactivity Disorder, Conduct Disorders, or Learning Disabilities because these are also highly prevalent categories of disability with deserving and similarly needy children and families. Parents of children in any of these categories could persuasively argue they and their child lack explicit and specialized services. An Office of ASD risks generating resentment, antipathy and competition across communities of families, providers, and professionals as it appears to place one category of need up against another.

Referencing a 'public health crisis,' Chapter 3 of the Commission's report begins with policy recommendations stating health plans should "provide a full range of medically necessary services...for ASD" (2007, p. 30). The chapter, however, never actually offers guidance or detail towards which "medically necessary services" are consistently and uniquely required for persons with ASD. As a result, the matter continues to dangle precipitously allowing conjecture, contention, and emotion to drive the discussion. Furthermore, whether persons with ASD have agreed upon medical needs or consistently required medical treatments remains a highly controversial and disputed service model (Johnson & Myers, 2007; Offit, 2008).

The recommendation for health plans to provide 'medically necessary services' to those with ASD is premature due to the dramatic heterogeneity typically seen in persons with ASD and since studies intended to establish a broader understanding of the medical profiles present in ASD are on-going and continue inconclusive (Rutter, 2005; Szatmari et al., 1995). The risk increases as parents and others become increasingly driven to try unproven, expensive, often time intensive and inconsistently productive medical interventions with their children with ASD.

The Commission's report risks further clouding the importance of research validated behavioral, instructional and related interventions rather than offering helpful thoughts or shedding any real light upon the issue. The Commission should have offered a clear definition of research validated intervention practices as it relates to treatment efficacy, viability, safety and applicability.

For this reason, health plans can hardly be mandated to "provide a full range of medically necessary services" for persons with autism because that 'range' has neither been identified nor agreed upon between medical and related clinical professionals (Baird et al., 2003; Offit, 2008; Wagner & Lockwood, 1994). Biomedical and related interventions cannot yet be recommended based on a diagnosis of autism alone in the same way that insulin is ordered for Type I Diabetes or bronchodilators are prescribed to those with asthma.

Too often, specific medical recommendations are categorically offered for those diagnosed as having ASD, and it is disappointing that the Commission's report referenced "...medically necessary services" (p. 30) without question or discussion. In fact, there is a growing body of literature that not only questions the efficacy of particular biomedical treatments but has identified specific risks to children who undergo some of these treatments. These treatments can range from chelation and nutrition, to mega doses of vitamins, and injections of Lupron (Levy et al., 2007; Offit, 2008, Seidel, 2006).

Chapter 3 of the Commission's report goes on to reference the need for "all health plans to treat autism as a neurological condition..." in the same domain as "...stroke and other neurological conditions" (2007, p. 29). In fact, the constant reference to the supposed medically-based "symptoms" of ASD may mislead professionals and families into the misperception that there are immutable and stable characteristics of ASD which are predictable across persons with the diagnosis. If specific behavioral characteristics were stable symptoms across all with an ASD diagnosis, consistent diagnostics could be done and treatments selected that would be consistently effective and successful in all of the ASD diagnosed population.

Instead, the reality is that ASD often leads to multi-faceted and highly heterogeneous areas of disability which can impact children very differently (Szatmari et al., 1995; Walker et al., 2004). Persons with autism can be very different with regards to their levels of social and cognitive competence and behavioral functioning. Though persons with autism often share specific behavioral and cognitive characteristics with individuals with Down Syndrome and Fragile X (Heward, 2003), these similarities do not make them all one disability category. Like Down Syndrome and Fragile X, autism is a developmental disability with a neurological impact rather than a neurological condition or illness.

ASD does not explicitly or consistently 'cause' specific symptoms in the same way as asthma is linked to wheezing or epilepsy to seizures. Instead, autism reflects an increased probability that certain clusters of typical and observable human behaviors may occur at differential levels of frequency and intensity as compared to the general population. But, even then, subsequent behaviors are based more on social, learning, and reinforcement history; context and environment; previous history and experiences; cultural and systemic values; individual temperament; and transactional relationships (Horner et al., 2002; Mandel & Novak, 2005) than either the autism or perceived 'medical necessities.'

The constant referencing of ASD as an on-going medical and public health crisis is therefore highly problematic and counterproductive. In this author's view, children and families would be much better served by a view of autism as a crisis of instruction and learning whereby environmental restructuring and family supports, along with behaviorally-based intervention and individualized instruction, would be prioritized.

ASD is not a medical or psychiatric condition at all but a developmental disability (Heward, 2003). The fact that other developmental disabilities, such as Down Syndrome, Fragile X, and Cerebral Palsy, very often have specifically associated neurological, cardiac, and/or GI implications has not led to these disabilities being classified as a "neurological condition" or "public health crisis" or demands for comprehensive coverage by health plans. Nor have instructional, behavioral, and social supports for these disabilities been equated with medical 'therapy' as the Commission's report broadly indicates they have been for persons with ASD.

Instructional practices based in a behavioral analytic model starting with early intervention are known and widely accepted as a method towards ameliorating behaviors which may manifest in persons with ASD and interfere with individual learning, social, and personal success. Effective early behavioral intervention and effective instruction includes a reduced need for modifications and more intensive intervention over time (Koegel & Koegel, 1998; Lerman, et al., 2004). Even the most effective instruction and structural modifications typically will not generate similar outcomes in true neurological conditions.

As already discussed, autism is not a homogenous disorder, either medically or behaviorally. Autism continues to be differentially diagnosed and extensive literature exists about the challenges of, and the unique features to be considered before, giving an autism diagnosis to a child (Mandel et al., 2002; Wagner & Lockwood, 1994). In children with ASD, there typically exists great variability in cognitive, adaptive, behavioral, social,

developmental, expressive, and social functioning (Heward, 2003; Szatmari et al., 1995). This variability means that while one clinician might diagnose autism, another may easily and reasonably come up with a different diagnosis. Studies over the past few years have noted that autism is now routinely diagnosed for persons who would have been otherwise diagnosed just a few years ago to include those who more correctly fall into the category of communication disorders (Bishop, et al., 2008).

The diagnosis of autism remains highly debated and under the influence of multiple variables. Autism 'prevalence' can, in part, also be predicted based on data related to demographics and/or ethnicity (Beeger et al., 2009). Of particular note is that autism prevalence can actually fluctuate based on income and neighborhood thereby risking a disproportionate concentration of money and resources in specific communities while largely overlooking others. Children living in poverty are too often identified as either mentally retarded or emotionally disturbed by schools while children living in suburban and higher income school districts are more likely to be classified as having learning disabilities or autism (Lauritsen et al., 2005; Singer et al., 1989). Clinician training, areas of specialization, professional influences, and personal frame of reference may also directly influence diagnostic decisions and outcomes (Caplan, 1996).

The Blue Ribbon Commission on ASD further implies that the field has not agreed on a definition of 'best practice' for persons with ASD. This contention, however, is inaccurate. Best practice refers to outcomes generated by studies that are replicable, objective, generalizable, and refutable (Alberto & Troutman, 2006). While the etiology of autism remains a mystery, autism is not at all mysterious in that educators absolutely know how to teach even the most challenging children with autism (Simpson & Myles, 1998; Koegel & Koegel, 2006; Lerman, et al., 2004). The specific concern here is that the Blue Ribbon Commission's report on autism makes no effort to differentiate between studies that: (a) are consistently recognized under a true 'best

practice' model; (b) represent practices which may have promise (e.g. properly done experimental designs but with low numbers of initial participants and/or with viable anecdotal and qualitative returns); and (c) considered pseudo-science.

Many current biomedical claims and other treatments for ASD are disseminated in ways so as to broadly deny their refutability or replicability by external and objective researchers and clinicians. One primary example from a few years ago was when the promoters of Facilitated Communication (FC) claimed objective clinicians and researchers could not initiate studies of the procedure because it would risk the 'rapport' with those being facilitated. In other words, FC would never be effective when studied by other objective researchers (Offit, 2008). Promoters of FC subsequently utilized testimonials, hypothetical data, and other unsubstantiated anecdotal evidence to argue for their model.² FC was ultimately recognized as invalid for persons with ASD and has largely left autism services. Such problematic clinical practices, however, continue across a number of current biomedical and intervention models (Bodfish, 2005; Jacobson, et al., 1995; Offit, 2008).

The Commission's report only made passing references to these concerns and, even then, only to point out that there are many honest and sincere differences of opinions between parents, schools, clinicians, and service agencies. The Commission is correct to say that there are many honest differences of opinion among well intended and well-meaning persons. To assume, however, that each opinion has equal weight, veracity, or benefit for children with ASD and their families is, at the least, problematic and, at the most, dangerous. Even honest and sincerely held opinions do not simultaneously infer legitimacy.

² The author listened to such a presentation by advocates of FC at the annual conference of the Association for Behavioral Analysis in San Francisco in 1993.

Today's reality is that far too many of the currently available biomedical interventions clearly fit the criteria for pseudoscience, which is defined as treating as a science those variables and components which clearly are not. Pseudoscience includes:

- Demonstrations of benefit based on anecdotal evidence and unsubstantiated testimonials;
- Indifference to baseline abilities and the potential for spontaneous improvement based on maturity, parallel instruction, and environmental impact;
- The disavowal of related or alternative scientific procedures;
- Claims that attribute lack of success to the family (or other caregivers/providers) doing something wrong; and
- Refusal to expose the methods and protocols to a clinical peer review process, thereby allowing replication of the claimed results only by those with a primary investment in the outcomes (Jacobson et al., 1995).

Numerous families, teachers, and other direct providers of children with autism and other special needs can share stories about being handed poorly constructed interventions that did not work. Rather than assuming responsibility for resulting problems, the involved professionals too often claimed the problems were the result of either poor implementation or understanding by others (Albin & Sandler, 1997; Sandler, 2001). Similarly, certain biomedical interventions are often provided in isolation under the mistaken belief that critical behavioral, instructional or other home-based interventions will either interfere or are, simply, not necessary.

Many of these biomedical interventions are expensive and inconclusive in their benefit. Furthermore, some of these interventions can be dangerous and children with ASD have been injured, even killed (Offit, 2008). Everything and anything simply cannot be considered as 'on the table' with regards to services to persons with ASD. The Commission's report left families, providers, and service agencies with little guidance or even the most fundamental criteria as to what should (and should not) be

considered within an intervention and support model for ASD.

Of course, the current lack of guidance and these stated concerns should not mean treatments which may not be considered viable for children and adults with ASD now would be forever off limits. Instead, there should be clearly stated criteria regarding (1) what is acceptable, and what makes it acceptable; (2) how an intervention that is not now acceptable might become acceptable; and (3) what interventions will remain unacceptable and why.

Instead of providing a direction and an emphasis on those recognized and existing instructional, behavioral, psychological, medical, and social supports that can make a difference in the lives of children with ASD and their families, the report goes on to emphasize the need to "monitor, assess, and translate important neurobiological and biomedical advances and other scientific breakthroughs rapidly occurring in ASD research" (California Blue Ribbon Commission Report on Autism, 2007, p. 43). The report fails to identify specific 'breakthroughs' while correctly acknowledging later on "...there are no widely accepted guidelines on exact program components of effective ASD interventions" (p. 54). The fact that the Commission's report did not clearly and effectively define the difference between best practice, promising practice, and pseudoscience will continue to challenge and increase the likelihood of a crisis with regards to the relationships between families, clinical providers, and service agencies in California and across the country.

With regards to these differences in opinion, the Commission's report (2007) goes on to acknowledge that it is "(not) clear what constitutes optimal treatment based on an individual's age, symptoms, and level of functioning" (p. 54), that "parents, services, and experts may come to different conclusions about the needs of a particular child" (p. 55), and that there is a "shortage of trained and qualified providers" (p. 55). The Commission still insists, however, "service agencies (remain) responsible for providing appropriate interventions

regardless of cost or availability of providers [italics added for emphasis]" (p. 55). Beyond the incongruity and risk present in this statement, it appears to open the door even wider for more conflict, litigation, and expense between families and service agencies, while failing to provide direction, proper resources, or acknowledgement of what is known to be effective for persons with ASD.

It is quite possible that the "complexity, intensity, and economic costs of services to individuals with ASD" (p. 12) identified by the Commission risks being further intensified by this report. After all, how can schools or service agencies, like California's Regional Center system, be expected to compete with the neurobiological, biomedical, and neurological models of ASD continually emphasized but never delineated? The strengthening of effective community-based services and supports with an emphasis on the schools in combination with an instructionally-driven, behaviorally-based intervention model should be prioritized for children with ASD. Effective instruction is the key while differentiated and individualized lesson planning should be the focus (Tomlinson, 1999; Wehmeyer et al., 2002).

The fact that the Commission listened to and considered a wide range of testimony and feedback is commendable. This author was strongly drawn to the message of collaboration and interagency cooperation, a point the report strongly supports to include the benefit of 'demonstration projects' both from within and across service agencies towards the enhancement of a seamless set of family and child-friendly services. The Commission should move strongly towards validating and strengthening the range of services and instructional models which are currently in place.

The key is to first recognize the available resources, knowledge, investments, and services that currently exist, and to offer renewed funding, training, and oversight via applicable public agencies to include the schools, social services, and the regional center system. Without this awareness, the Commission's

prediction of extreme and escalating costs of services to children with ASD and their families is more likely to become a self-fulfilling prophesy.

The issues confronting children and adults with ASD and their families are truly confounding and will continue to demand serious attention. The potential to disconnect children with ASD and their families from other children with developmental and acute learning needs and their families in schools and across the community seems illogical because many of these needs are closely interconnected. A related concern is that the Commission's report may risk placing families of children with ASD and those who have children with other disabilities and learning needs in direct 'competition' for attention and resources, even though the resources and knowledge will comparably serve children in both groups.

Finally, autism risks being turned into a class based disorder whereby prevalence rates, service availability, and professional resources are substantially more concentrated in higher income suburban areas than in lower income urban neighborhoods. This likelihood, alone, requires greater examination and consideration regarding the overall prevalence rates of ASD that were identified and discussed in the Commission's report. Such prevalence by demographics (Beeger et al., 2008; Lauritsen et al., 2005; Mandel et al., 2002; Singer et al., 1989) would also appear to directly challenge a unique biomedical model for autism leading to the claims of a public health crisis. Children with autism may be better served if autism is used as an umbrella term or disability category; autism may be considered as 'types of autism' rather than as having a single attributable process (Szatmari et al, 1995; Walker et al., 2004).

Recent genetic studies of persons with autism have identified the likelihood that multiple sets of genes may be involved in ASD with different actions, interactions, and outcomes driven by a number of confounding variables to include ethnic history (Beeger et al., 2008; Muhle et al., 2004). Although increasingly clear evidence

exists which identifies autism as a multifactorial disorder, there continues to be an inadequate understanding of the genetic and non-genetic variables involved and how they interact (Rutter, 2005). Therefore, it is not reasonable to presume either a unique biomedical model currently exists or a full range of medically necessary services for persons with autism has, or can be, identified at this time.

The use of charged language to describe ASD as an 'epidemic' or 'public health crisis' distracts from the human factor while diminishing the need for environmental, individual, instructional, and quality of life change. This change should start with an application of the resources and knowledge currently in place. The on-going 'crisis' mode further risks creating conditions that foster more detached and frenetic movement and treatment activity ranging from the overuse of medications and extremely

expensive and unproven biomedical treatments to unnecessarily invasive instructional and intervention strategies that deny and ignore individuality and uniqueness. The continued over emphasis of the bio-medical and 'crisis' model in the Commission's report and across the field of ASD risks becoming a tremendously inefficient and costly distracter, as well as a real disservice to children, their families, and communities.

A renewed focus on the broader system of services, including instruction, structural supports, and collaboration for sustainable change, will better serve children with ASD and their families as well as assist other children with special needs and their families. To assume otherwise risks wasting available and invaluable resources while nurturing a cycle in which each group will be forced to 'reinvent a wheel' for themselves that, in actuality, already exists.

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