

## **CHALLENGES IN INTEGRATING EDUCATION AND HEALTH CARE**

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As my attached resume indicates, I have had numerous professional, personal, and public policy roles in health care and education over the past 36 years. I am submitting this paper as an individual and not on behalf of any of the organizations with which I am affiliated.

### **I. EXECUTIVE SUMMARY**

**1.1** How schools, healthcare, and social services provide services is based on an understanding of human behavior that current science shows to be incomplete and, in some cases, wrong or counterproductive.

**1.2** Despite a growing appreciation of the need for flexible collaboration across education, health care, and social services, few people appreciate the obstacles presented by the service models, funding, location, and workforce training within these distinct systems of care. Other obstacles arise from basic features of human behavior. One must understand the different types of obstacles in order to propose effective solutions.

**1.3** We need to pilot and systematically investigate not just programs, but institutional design. This could require waivers from both federal and state legal requirements, as well as the recruitment of volunteering organizations within education and health care. Autism services is a good place to start, given that autism raises the very issues of social emotional development that are critical to improving services for all other students.

### **II. INTRODUCTION**

It is now clear that raising and educating children to meet our desired goals for knowledge, job readiness, and self-sufficiency requires good schooling, strong social emotional supports, safe environments, and adequate food, housing, and physical and mental health. It is also now clear that many children lack one or more of these “ingredients” during at least some of their school years. Moreover, challenges in any one of these areas can affect the others. Yet, although there are a number of public and private agencies serving children and their families, most of these agencies are designed to address a single type of service need. Viewed from the perspective of the child and family, their services are fragmented, uncoordinated, and often insufficient, leaving important needs unmet.

This paper addresses a small but revealing slice of this interconnected set of challenges, namely the needs of children with autism. For the past nine years the Oregon Commission on Autism Spectrum Disorders has been engaged in trying to

improve and coordinate services across service systems and agencies throughout the state. The lessons we have learned shed light on some of the changes needed for all students, not just those with autism or disabilities.

### **III. WHAT AUTISM HAS TO TEACH US**

As most people are now aware, autism is a developmental disorder that disrupts a child's social and emotional functioning from birth. Although it affects only about 1½ to 2 percent of the population, it has had an outsized impact by driving basic research on the biology and psychology of social emotional development. Autism research is part of a large and growing body of scientific evidence establishing the crucial role of social emotional interaction in development across all areas of human functioning, including what we consider our "crown jewels" of cognition, language, culture, and morality, at both evolutionary and individual timescales. Attachment 1 outlines the specifics of this scientific revolution in human behavior. This is precisely the opposite of the widespread view that cognitive skills and computer literacy are our most pressing needs. And it goes a long way toward explaining why our current systems of care are not delivering the results we want. Simply put, if we want students who are ready to meet life's challenges, we need to understand that ***all*** behaviors draw on the full range of human functioning: social, emotional, cognitive, and physical. We need those who touch the lives of students to understand how these pieces fit together, and we need structures that allow our institutions to coordinate with each other as the needs of students dictate.

### **IV. STRUCTURAL OBSTACLES TO SERVICE SYSTEM COLLABORATION**

Our health care and educational institutions cannot currently collaborate in large part because their funding, service models, physical locations, and workforce training are incompatible. Starting in 2006 under the auspices of the Oregon Pediatric Society, I led a work group on identification and assessment of autism that brought together leaders in autism services from both education and health care. It was literally the first time that they had been in a room together. It took about a year and a half of monthly meetings to develop a common vocabulary, to clarify "how the other half lived," and to correct mistaken views about the services each half mistakenly thought the other was responsible for providing to children. These and other obstacles are outlined below.

#### **Obstacle 1: Service Models, Funding, Location, Training**

**Physical health care:** Although the system is starting to evolve, it remains driven by single episodes of care to individuals in isolated care settings. Apart from hospitals, those who actually provide services are paid on a fee for service basis and must document each episode of care in the medical record in order to qualify for funding. If the provider cannot document substantial improvement over short time frames, many ongoing types of services cease to be funded (e.g., physical and speech therapy). Other controls on utilization include fixed limits on the number of visits

per year in a given service category such as speech therapy or physical therapy. The health care system is characterized by a high degree of specialization, which means that much of the workforce is focused on only a narrow slice of functioning. For the most part, physical health professionals lack training in affective neuroscience or mental health. The system was designed to address acute care for the previously healthy. Thus, except for pediatricians, they generally lack a developmental perspective. Although things are improving, the system historically has struggled with chronic care, and even more with the social and physical environment that surrounds an individual's physical care. Individual professionals are generally located in clinics where they are incentivized to see as many patients and provide as many unique services as possible from morning to evening. They are generally not compensated for collaborating with each other or with educators, and are generally not available for collaboration until after 5:00 p.m.

**Mental/behavioral health:** The service model of mental health is basically the same as that of physical health, with two major exceptions. First, it incorporates greater levels of group treatment. Second, it is greatly underfunded relative to physical health, and, consequently, there is a dearth of well-trained providers. There are great pressures to deliver mental health services through the lowest cost providers. Licensing boards vary in their training requirements, with most deferring to national accrediting bodies (for training programs and/or individual certification), but no cross-discipline minimum training standards geared to specific conditions or issues (e.g., ASD). In the case of licensed social workers, there is a tremendously broad scope of practice, but almost no training standards, with individual practitioners and/or their employers free to determine what they are qualified to do.

**Education:** The service model of education is one of daily service delivery to age-matched groups of children. Although preschool and early elementary school programs place a greater emphasis on social emotional development than the K-12 system, the group service model presumes that children have met birth to three social emotional and cognitive benchmarks that make group learning possible. (Thus, the system is specifically not designed to address students whose social emotional development impedes their participation in the basic service model.) And, of course, the primary goal of education is to impart information and foster cognitive development, which age-grouping assumes to follow a relatively uniform age-dependent developmental path. School districts are funded through fixed per student payments from the general fund, supplemented by local levies of various sorts. The only required daily record-keeping is student attendance. Given a variety of financial pressures, schools have prioritized classroom teachers. Educators (general education, special education, SLPs, school psychologists, administrators) are not required to have a substantial background in early social emotional development, neuroscience, or psychopathology and are, generally speaking, unaware of current scientific findings in human behavior. Many districts do not have access to school psychologists, and where they do, school psychologists have caseloads so high that they cannot effectively support individual students. Oregon

has many fewer school psychologists per capita than other states, which likely results from a perceived lack of necessity and/or legal requirement (in contrast to speech-language pathologists, who are compensated at basically equivalent rates, but who are available in every school building, however sporadically). School psychologists are most frequently used for psycho-educational testing, because certain evaluations for special education can be administered only by school psychologists. According to a survey performed by OCASD, many of them believe that their skills are being underutilized (whether their skills lie in the direction of individual student counseling or in the direction of managing special education services for children with neurodevelopmental disorders). Even so, school psychologists are not required to have substantial or broad training in neuroscience or psychopathology in order to obtain licensure. Preliminary investigation into the training programs in Oregon has revealed that school psychologists can be licensed in Oregon without any substantial training in the identification and nature of autism, and the same is undoubtedly true for other neurodevelopmental disorders. While some districts have school-based health services, these are more commonly available in high schools, and many school buildings lack them altogether. School nurses used to be common, but are now rare, and where they exist, commonly have very large caseloads. Teachers and other educational professionals generally end their day by 4:30 p.m. They are thus unavailable when health care professionals from outside the building are available for collaboration. In order to collaborate with health care professionals during the day (if, for example, a health care provider is willing to speak with an educator over the lunch hour), substitutes must cover their classrooms or services, imposing substantial costs on the district.

**Public Health:** Few people realize that public health rather than individualized health care is responsible for something like 90% of the increase in lifespan and human health over the past 150 years. Public health initiatives such as screening, vaccination, mosquito control, sewage treatment, and nutrition programs have all made significant contributions to health. Public health approaches such as universal screening could contribute to addressing many of the challenges facing students and schools.

## **Obstacle 2: Tribalism**

A useful way to view individual professions and larger care systems such as education and health care is through the lens of tribalism. Tribalism has been a basic feature of human society throughout history. Tribes engage in intense competition with one another, punctuated by brief occasions for friendly exchange, until they are confronted by an external enemy. They then assemble into larger scale clans to defend themselves, seek redress, or claim new territory. In this analogy, the larger care systems such as education, health care, and social services operate like clans and the individual professions or care organizations/school buildings operate as tribes. Those to whom services are provided (patients, students, clients, families) and members of other professions are not part of the tribe, or even, sometimes, of the clan. The existence of care tribes presents a specific barrier to coordination of

care among professionals and parents whose diverse types of expertise are all needed in the care of an individual child. It also can interfere with efficacy in the practice of one's own profession: it is all too easy to locate the cause of poor outcomes in factors controlled by out groups. (It's the parents' fault that this child is not behaving; health care/the educational system/social services should be addressing this, not us). To the extent that we can escape our clan and tribal blinders, we do so by reflection, acknowledgment, and ongoing exchange with those in other tribes.

### **Obstacle 3: Money**

Within every system of care, professionals feel that they lack sufficient funds to do everything they would like to do or believe is necessary.

### **Obstacle 4: Turnover**

Turnover includes any change in staff providing services, whether from individual service providers leaving their positions to changes in grade level, student/patient geographic moves, or changes in health insurance. The effect of turnover is to destroy relationships and the knowledge base of the individual provider about the individual child. (Try this thought experiment: imagine if you had to leave your family and move to a new one every year or two.) Turnover is an especially acute problem in education. Every single year in elementary school students encounter a new teacher who knows virtually nothing about them. In middle and high schools, students may encounter multiple new teachers a year. This may or may not be as true for special education students and staff if the student continues to be located in the same school. However, in Portland, where my son attended school, special education programs and staff were regularly moved from building to building at least every two or three years. Administrative staff are also regularly replaced at all levels of education, resulting in institutional memory with critical gaps. Turnover can also be a problem in health care, if a child moves or their health plan changes and the new plan does not cover the child's previous provider.

### **Obstacle 5: Public and Family Distrust**

Pick any system of care described in Obstacle 1 above, and you will find a horde of people who distrust it, for reasons both well- and ill-deserved. It is safe to say that all of our major systems of care have been established by providers of care without substantial and regular input on how they work for the individuals being served. Patients, students, and families correctly perceive that they are not a part of the care tribe or clan, and thus often correctly perceive that some of their legitimate needs are not a priority. Moreover, they often have limited understanding of how these systems work, because people who work in them don't fully appreciate knowledge gaps, don't understand how it affects their professional effectiveness, or don't believe it is their job to explain how they work (which many don't fully understand themselves). Moreover, human behavior suffers from many predictable

weaknesses, whether the humans are in government, for profit, nonprofit, social, or family settings. Finally, religious and ideological hostility to both public and private systems of care mean that no set of arrangements, however appropriate, will garner universal public support.

### **Obstacle 6: Lack of Knowledge**

We are now in the unfortunate situation of now knowing a few reasons why our systems of care are falling short, but we lack a consensus on what improved systems would look like. Most important, we are still at the beginning stages of understanding human behavior. Premature efforts to incorporate the current state of science into universal public policy can have disastrous consequences, for example the theory of evolution, which devolved into the eugenics movement, justifying mass sterilization and genocide of culturally undesirable groups. Legitimate concerns have been raised about the pathologizing of typical behavior, such as grieving, and there is no consensus on how to factor new understandings of human behavior into health care, schools, social services, or criminal justice.

## **V. POLICY RECOMMENDATIONS**

### **5.1. Ultimate solutions**

**5.1.1 Blending and co-location of services.** Services should be available where children are located: as close as possible to home and school. Co-location and blending are the only practical ways to identify and address some issues. Rural areas are especially challenged when it comes to access to many types of health care services. Telemedicine is increasingly common in health care, but has yet to make significant inroads in education.

**5.1.2 Blended funding.** At least where it comes to children, we need to develop mechanisms to blend funding to support collaborative and developmental service models. This includes such challenges as documentation of services, limits on number of services per year, and predetermined outcomes expectations.

**5.1.3 Enhanced screening.** Enhanced screening can identify problems at earlier stages when there is a greater possibility of effective intervention.

**5.1.4 Universal workforce training in human behavior.** Workforce training is necessary both to avoid counterproductive attitudes and to permit the development of more realistic solutions.

**5.1.5 Enhanced parent training and engagement.** Parents are extrinsic to the basic service models of health care and education. However, the revolution in human behavior suggests that they are in fact central to all aspects of education and health care. In an ideal world, we would be finding multiple ways to reach and teach

parents/caregivers and to design services to engage them in their child's development in healthy ways.

**3.1.6 Incorporation of human behavior into the curriculum at all levels of education.** It is shocking that in the 21<sup>st</sup> century all students who graduate from high school are expected to know something about trigonometry and history but not the science of how human beings work. No matter what job students have after they leave school, they have to deal with people for the rest of their lives.

## **5.2. Intermediate Steps: Pilots With Data Gathering and Matched Controls**

Oregon has a long history of innovation in health care, including a focus on outcomes. This history should now extend to the blending of health care and education.

### **5.2.1 Pilot Blended Models in Both Urban and Rural Settings.**

The dynamics of health care and the availability of certain types of school personnel are substantially different in urban and rural areas. Therefore, any pilots would require taking these differences into account.

#### **5.2.1(a) Start With ASD: Something Small That Can Shift Basic Understandings**

As a neurodevelopmental disorder, autism cuts across socio-economic and racial/ethnic divisions, and it does not engage some of the hot button political issues of personal moral responsibility that drug addiction and poverty do. It also raises in the sharpest possible way the very issues that professionals most need to address in other areas of service delivery. This combination offers an opportunity to begin the reorientation process in a relatively isolated and nonthreatening corner service delivery.

The Oregon Commission on Autism Spectrum Disorder does not currently have any proposed pilots, but could possibly develop voluntary rural and urban pilots for the identification of children with ASD and collaborative service delivery under the guidance of appropriately trained mental health professionals. To be effective, such a pilot would require building-wide training in the social emotional aspects of human functioning. Development of such a pilot would require the active engagement of ODE and DHS, as well as the districts in which the pilots would run. It would probably take on the order of two years to develop.

## **ATTACHMENT 1**

### **THE SCIENTIFIC REVOLUTION IN HUMAN BEHAVIOR**

Our current major agencies and systems of care date from the middle of the 19<sup>th</sup> century through the early 20<sup>th</sup> century, when the understanding of how people work was very different. Most of us still use one or more of the following models of human behavior for our day to day judgments, predictions, and service delivery:

- **Assumption 1.:** Human beings have free will; when they do not conform to social norms or engage in behaviors that will ensure their long-term well being, it is because they have chosen not to or because their families have not taught them right from wrong
  - **Corollary 1.1:** giving people more information on a given topic will cause them to make the right decisions
- **Assumption 2:** Human brains are like mechanical recording and storage devices: they faithfully record what occurs in the environment and then store the information in some kind of neural filing cabinet for faithful reproduction and use as required on subsequent occasions; this process is independent of other aspects of human functioning
  - **Corollary 2.1:** cognition is separate from social and emotional functioning; if schools just use the right teaching strategies, all children will learn
  - **Corollary 2.2:** cognition is separate from internal sensory systems and self-regulatory areas of the brain
  - **Corollary 2.3:** the overwhelming majority of people operate exactly the same way; only a small minority of students are different enough to merit special accommodations or services
- **Assumption 3:** Human bodies are isolated biomechanical and biochemical machines; health care problems can be addressed through medical interventions and drugs delivered in care settings or processes outside the patient's daily environment and social emotional functioning
  - **Corollary 3.1:** patients understand their doctors' instructions and will follow them
  - **Corollary 3.2:** mental/behavioral health is unrelated to physical health
  - **Corollary 3.3:** individual patient care is the primary driver of individual health; social and environmental influences are secondary in importance

The past 40, and especially the last 20, have seen an explosion in the scientific research on how human beings evolved historically and develop and behave in modern environments. This research, which has converged across numerous disciplines, has shown that each of the above propositions is either wrong or so incomplete as to be misleading when it comes to solving our major policy challenges. While we remain at the beginning stages of learning how the brain works and individual children develop, the following propositions better capture the complexity and dynamics of how human beings operate:

- **Assumption 4:** The brain orchestrates all human behavior in order to (a) maintain the body's internal milieu within a narrow range of temperature and chemical concentrations necessary to support life (homeostasis), and (b) reproduce. Practically speaking, this means obtaining food and shelter, cooperating with others, and defending oneself in hostile environments. Internally, the brain consists of several major systems, *all* of which are *always* online and *all* of which contribute to producing behavior. Cognition is the system that uses external sensory systems to monitor and understand the external environment. Emotional functioning is the system that uses both internal and external sensory systems to prioritize the body's homeostatic needs and prepare the body for appropriate actions. Emotions tune cognitive processing according to the body's highest priorities. As one of the major systems of exchange with the environment, the motor system both effectuates action and also contributes substantially to cognition in multiple ways. Each of these major systems has subdivisions, some of which continuously cooperate and others of which predominate or displace others according to the context and the brain/body's current priorities. The vast majority of brain functioning is fast, unconscious, and predictive: unconscious processes prepare the body to respond to what the brain *expects* to happen next. Unconscious processes thus greatly influence what individuals perceive and what is available to consciousness at any given moment.
- **Assumption 5:** Human beings are among the most social species on earth, and it is precisely their sociality that has enabled them to thrive in diverse environments over the entire planet. Human sociality is underwritten by both multiple social motivations and social cognition (understanding the actions of others, creating shared understandings of the world, and creating shared roles to perform mutually beneficial actions). Social functioning is essential for human survival and deeply affects cognition in seemingly unrelated domains.
- **Assumption 6:** Before birth, brain development is genetically guided, largely but not completely insulated from environmental influences. After birth, the brain continues to develop and change over the lifetime, with two key periods of very substantial development: the first during the first three years of life and the second in late adolescence. Brain development during

the first three years of life is overwhelmingly a result of social emotional interaction between caregivers and the child. Sensitive, individualized, and responsive caregiving literally changes the brains of young children in ways that affect them throughout life, including their capacity to parent their own children, ***and even aspects of their genetic code***. This process sets up what is known as social emotional reciprocity, which in turn is the foundation and pattern of all cooperative human interaction. When it is disrupted due to prenatal brain development or postnatal environmental conditions such as neglect and trauma, development and functioning are seriously impaired.

- **Corollaries of Assumptions 4, 5, and 6:**

- A.** Infants and children choose neither their prenatal brain development, nor their physical and caregiving environments, both of which have profound influences on their ability to learn and conform to social norms. Human relationships, in school and outside of it, have at least as great an impact on learning as cognitively focused teaching strategies, although we of course need to develop and use the most cognitively sound teaching strategies.
- B.** Because the brain operates predictively based on past experience, people who share the same physical space do not all perceive or understand events in that physical space in the same way.
- C.** Cognitive strategies and drugs help many people, but are not sufficient, alone or in conjunction to address the developmental needs of all students.
- D.** Many more children than commonly understood, from all backgrounds, experience both genetically and environmentally produced challenges to learning. For example, skyrocketing rates of anxiety, depression, eating disorders, and drug addiction cross socio-economic boundaries. Visual and auditory sensitivity that does not rise to the level of a medical condition can make classrooms highly distracting to many children. We need a better understanding of the extent and types of challenges students experience, and how these affect learning, in order to design better classrooms and teaching strategies for ***all*** children.
- C.** Because all brain systems are continuously interconnected, what we call mental, social, or emotional functioning affects physical health and vice versa. Recent research has shown that adverse childhood experiences, including racial discrimination, affect physical health throughout life via the effect of stress hormones.

**BACKGROUND READING:** Robert Sapolsky, **Behave** (2018), a masterful review of the human sciences written for a lay audience by a Stanford professor of biology and neurology.