

Conference Paper

The Emergence of the American Academy of Developmental Medicine and Dentistry: Educating Clinicians about the Challenges and Rewards of Treating Patients with Special Health Care Needs

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Abstract: *Expanding the exposure of medical students and residents to persons with special health care needs has been a challenge. The purpose of this paper was to describe the development of the American Academy of Developmental Medicine and Dentistry, its principles, and its 5 essential concepts. (Pediatr Dent 2007;29:134-7)*

KEYWORDS: PERSONS WITH SPECIAL HEALTH CARE NEEDS, EDUCATION, AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY, PHYSICIAN TRAINING

Several years ago, health care advocates, clinicians, and believers in oral health care for persons with special health care needs (PSHCN) pushed for the adoption of clinical experience for both dental students and dental hygiene students. Drs. Sanford Fenton, Steven Perlman, and others laid out the route to have their proposal reviewed, considered, and adopted. I had the opportunity, as a physician, to testify before the Commission on Dental Accreditation (CODA) at their meeting in San Antonio, Tex.

Things appeared quite promising, as CODA had both the wisdom and opportunity to help fortify the next generation of dentists by assuring that clinicians would have the skills to care for PSHCN across their lifespan. At the 11th hour, we were notified there might be a change in the language of the mandate. The word "required" would be deleted and "recommended" would be substituted. This would have been the death knell for our vision. At the last minute, several of us decided to write individual appeals requesting that CODA not dilute the intent. Since I wear many hats, I had many letterheads from which to choose. I could have used stationery from the University of Tennessee, *Exceptional Parent Magazine*, or the Habilitation Center at Orange Grove. Of course, I went for the most impact and used the letterhead from the President's Committee on Mental Retardation. I figured this effort was worthy of bringing out the big guns.

I sent a letter with the seal of the President's Committee to CODA urging it to "require" clinical competency, not simply recommend it; after all I was the Special Liaison for Family Healthcare Concerns and this was, indeed, a major family health care concern. I proudly faxed a copy of the letter to the President's Committee to demonstrate that family health care concerns were being honored, and we were on the move. The next day, I came back into my office after lunch and my assistant said, "Dr. Rader, you have to return calls to your wife, your boat mechanic, several parents, and the White House."

The White House legal counsel called and said, "Dr. Rader, you are in violation of the federal law that relates to the misuse of your position as a member of a presidential advisory board." I asked what was the role of the Special Liaison for Family Healthcare Concerns and was told it was to advise the President on family health concerns, but not to actually do anything about it. I wasn't actually removed from my position; my position was dissolved. I am also sad to report that they have recently replaced the members of the committee, which they do every several years, and not one physician or dentist is represented.

So, once again, recommendations to improve comprehensive health care, including oral health, fell on deaf ears at the highest level.

I was proud to have fallen on the sword for parents, and I also remain very proud of CODA for requiring that the next generation of dental students acquire some modicum of clinical acumen in treating patients with developmental disabilities. That is something about which physicians and medical school deans cannot yet boast.

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Formation of the American Academy of Developmental Medicine and Dentistry (AADMD)

Several years ago, Surgeon General David Satcher hosted the first-ever task force on the health disparities of people with mental retardation. As was said in the movie "Casablanca," they rounded up "the usual suspects. The cadre of physicians and dentists who were in the trenches treating, teaching, doing research, and advocating for persons with developmental disabilities were either invited or somehow wormed their way in. One of the most important "take home" messages from Dr. Satcher was at the end of the conference when he said "Listen, I may have a real impressive sounding position, but there's not all that much I can do about the problem. You need to give this conference some wings and make something happen."

It was here that Drs. Henry Hood, Steven Zelenski, and Phillip May decided the best way to sprout wings was to formalize their interests and organize a bona fide Academy. They, like all of the subsequent members of the AADMD, belonged to other groups, associations, and academies that, quite frankly, were not delivering the goods in terms of creating an amalgam between physicians and dentists.

The AADMD today has great depth, promise, and an impressive track record in research, teaching, patient care, and advocacy. To the best of my knowledge, we are the only Academy that appreciates, welcomes, and acknowledges the role of both physicians and dentists working side by side in the pursuit of true interdisciplinary, not transdisciplinary, collaborative health care—for any patient population. We purposefully alternate a dentist and a physician as president.

The principles of the AADMD, as well as the 5 essential concepts that constitute our clinical belief system, most assuredly reflect your own principles of care. These AADMD principles are:

1. Patients with neurodevelopmental disorders and intellectual disabilities are valuable human beings, capable of the insights, feelings, and emotions that make human beings unique on the Earth.
2. Patients with neurodevelopmental disorders and intellectual disabilities have a right to be treated with dignity and compassion.
3. Patients with neurodevelopmental disorders and intellectual disabilities have a right to the same, generally accepted, community standards of health care available to the general population, regardless of their disability, age, or where they reside.
4. Our challenge as clinicians, teachers, researchers, and advocates is to solve the multiple problems that are the obstacles to that standard of care.
5. Our responsibility as physicians and dentists is to work together with our colleagues to assure, to the best of our ability, the delivery of that standard of care.

We encounter myriad syndromes and disorders with patients with developmental disorders. Consequently, clinicians preparing to care for individuals in this population—whether newly minted from medical or dental school or veteran department professors—need to have access to tools to enable them to: (1) see the big picture; (2) identify impediments to care; and (3) "deliver the goods." The "5 Essential Concepts of Developmental Medicine" is one of these tools. These concepts were authored by Dr. Phillip May, Professor of Developmental Medicine at the UMDNJ/Robert Wood Johnson School of Medicine in New Brunswick, NJ. They have been adopted by the AADMD and used in our clerkship curricula.

This is an abbreviated overview of the Five Essential Concepts:

1. The major functions of the brain include memory and learning, control of motor function, control of sensory input, and emotional regulation/control. These functions require that specific inter-related brain structures work together in a coordinated fashion. When these relationships are improperly developed or disrupted, dysfunctions will occur.
2. The underlying cause of this dysfunction is a biological disorder or—specifically for all patients with intellectual disability—a neurodevelopmental disorder that can be either.
3. Neurodevelopmental disorders will manifest as a clinical dysfunction of several primary symptom complexes or complications. These complications include:
 - a. cognitive impairment;
 - b. neuromotor dysfunctions;
 - c. seizures;
 - d. psychiatric disorders/abnormal impulse behavior; and
 - e. sensory impairment (as in blindness or deafness).
4. Depending on which of these 4 primary complications is present and its severity (some patients manifest all 4), the patient suffering from a neurodevelopmental disorder may also demonstrate a number of secondary conditions or health consequences resulting from primary complications. For example:
 - a. Intellectual disability and sensory impairment may increase chances of traumatic accidental injury.
 - b. Psychiatric illness may lead to poor hygiene and self-neglect.
 - c. Impairment of physical movement may lead to osteoporosis.
5. In addition to the complications and consequences of neurodevelopmental disorders, the patient with a neurodevelopmental disorder, depending on the precise etiology, may also demonstrate syndrome-specific conditions that may be multisystemic in nature and etiologi-

cally unrelated to the neurodevelopmental dysfunctions. Examples of syndrome-specific conditions include:

- a. mitral valve defects;
- b. cataracts; and
- c. Alzheimer's disease with Down syndrome or hypertension with William syndrome.

Medical educations and special needs

One of the reasons for the present quagmire of inadequate health care, at least in medicine, is the lack of formal training in developmental disabilities in medical school. The typical medical student gets a 45-minute lecture in dysmorphology that is usually part of a survey overview of embryology given in the first semester—usually in the first week of the gross anatomy course. The next time a medical student encounters a patient with developmental disabilities is in the third-year pediatrics rotation, and only if by coincidence a child presents who happens to have a developmental disability. There are no planned lectures, encounters, family exposures, or clinical experiences involving any form of disability. There are certainly no encounters, other than by chance, in the remaining core disciplines of surgery, internal medicine, obstetrics-gynecology, and psychiatry. If there is a “champion” of disabilities on the faculty, an elective may be offered, but it is simply by chance.

In fact, the same thing is true after medical school in the residencies. A physician can become a board-certified internist or family practice physician never having treated anyone with developmental disabilities. The situation in pediatrics is almost as grim, as residents are only now beginning to experience developmental pediatrics in general pediatric programs.

The discipline of neurodevelopmental disabilities is worthy, challenging, and rewarding, but not sexy. It is not sports medicine, it is not plastic surgery in Miami Beach, and it is not aerospace medicine. Patients with developmental disabilities are not attractive, inviting, or endearing—at least not to the uninitiated.

As a result, medical students (and possibly dental students) show little interest, curiosity, or excitement at the prospect of seeking elective clerkships in developmental disabilities. Generating interest now becomes a marketing challenge. Once they are there, the atypical presentations, clinical challenges, and unadulterated humanity of the patients can often seal the deal. Getting residents to show up is the challenge. I have found the best way is with an “in your face,” “take off the gloves,” and “shock and awe” approach. For example, when I was invited to present at the American Medical Student Association meeting several years ago, I submitted a presentation entitled “The Challenge and Rewards of Patients with Neurodevelopmental Disabilities.” Only 4 learners showed up.

When I was invited back, I discarded that title and pre-

sented “Funny Looking Kids, the Adults They Become, and the Opportunity to Give a Damn about Them.” I had standing room only. When I presented at the American Association on Hospice and Palliative Care, it was the first time this patient population was presented. It appeared in the course brochure as “The Emergence of the Hospice Patient with Developmental Disabilities.” Three learners showed up. Next time it was “Dying Retarded.” I had to repeat the session the next day for the overflow crowd.

A few days ago, I was invited to present to the Public Transit Association of Tennessee in Chattanooga. This was for the 250 directors, supervisors, and drivers who run the state's paratransit vans. They wanted to get a better appreciation for the culture, psyche, and needs of people with disabilities. I had learned my lesson and presented “Throw 'Em in a Boxcar”—Transporting the Blind, the Dumb, the Crippled, and the Retarded. Again, it was oversubscribed. The lesson here? Do whatever it takes to get them in. Then, it is up to you to intrigue, challenge, and ignite them. Sometimes, not always, it happens, and you see it in their eyes: A few of them get it.

The AADMD embarked on a research project to verify anecdotal reports that both medical and dental schools were doing a lackluster job in exposing students to the required competencies in treating patients with developmental disabilities. It was funded by the Healthy Athletes Program of Special Olympics and was named the Curriculum Assessment of Need (CAN). It has been completed and is currently awaiting peer review at a prestigious medical journal. The data were collected from medical students, medical school deans, dental school deans, medical residency directors, dental residency directors, and advocacy and patient care groups. In summary, the CAN project revealed what we suspected and feared: No one is doing much of anything. Across the board, students want to treat this population, but they felt unprepared. To the credit of the medical and dental school deans, they knew they were not preparing the students.

PSHCN are underserved

Hundreds of research papers, documents, and studies confirm that patients with neurodevelopmental and intellectual disorders are medically underserved. These reports come in binders from the Surgeon General, the Centers for Disease Control and Prevention, the Institute of Medicine of the National Research Council, the Office of Minority Health, and the Office of Disability. We would not be here if all physicians and all dentists had their fair share of patients with special needs sitting in their waiting rooms. But they don't.

As it turns out, the federal government has not officially recognized persons with developmental disabilities as medically underserved. This is in spite of their endorsement and funding of countless studies demonstrating that the root of

the health disparities lies in their being medically underserved. The Health Research and Services Administration (HRSA), the body that defines who is medically underserved, has not declared this population as being medically underserved. The HRSA should—in fact, it must. This is not because we need it to, although we do, but it has already created the mathematical equation that defines a population as medically underserved. So far, only certain Native Americans, some Eskimos, and some Laotian boat people are medically underserved. The equation, called the Index of Medical Under-Service (IMU), employs certain criteria, such as the:

1. percentage living below the poverty line;
2. percentage over age 65;
3. infant mortality rate; and
4. ratio of primary care physicians to patients in this group.

Dr. Matthew Holder, Executive Director of the AADMD, “did the math” and came up with a score of 54.1, well under the defining score of 62. HRSA to date has not acknowledged this.

AADMD initiatives

It is essential to understand the dynamics of stigma as the underlying fabric for disparities. Ideally, physicians and dentists should be the last to be influenced by stigma. Sadly, the reality is that stigma is responsible for women with Down syndrome not being given regular Pap smears, not receiving mammograms, and not being eligible for heart transplants. Stigma is responsible for problems such as:

1. thousands of patients not receiving baseline dental radiography;
2. thousands of persons receiving inappropriate psychotropic drugs instead of behavioral analysis and behavioral plans;
3. dental care being administered without a local anesthetic; and
4. the underutilization of hospice and palliative care at the end of life for people with developmental disabilities.

The recent establishment of “Label Me Not,” the Campaign for the Defeat of Stigma, is currently completing curricula specifically for health professions to create awareness of how stigma impacts the health care of PSHCN.

We are also behind in appreciating and treating people with the dual diagnosis of developmental disabilities and psychiatric disorders. We brush off depression, ignore schizophrenia, make cracks at sexual self-abuse, and “ho hum” suicidal ideation if the patient has a primary diagnosis of mental retardation. Mental retardation is not a diagnosis; it's simply the canvas on which these other footnotes are painted.

The future

We are struggling to keep up with the aging of people with developmental disabilities. They “tricked” us by not dying at a diminished age. The discipline of developmental gerontology is waiting for billboard space in the fields of: (1) medicine; (2) dentistry; (3) sociology; (4) health economics; (5) psychiatry; (6) neuroscience; and (7) assistive technology.

Another important topic is transition. Most clinicians can be persuaded to treat the cute, high-functioning, blue-eyed girl with cerebral palsy. Who wants to treat her when she is the noncompliant, aggressive, easily agitated 30-year-old with marked spasticity? We have women in their 40s receiving their gynecologic care from pediatricians, simply because there are no “takers.” We have to figure out a way to provide pediatricians with the confidence to refer these patients to an equally confident family practice physician who appreciates the resources in the community. We have to expand the “medical and dental home” across the lifespan.

We also have to contend with some significant concerns related to consent, restraint, reimbursement, and evidence-based practice. People with developmental disabilities who have not been adjudicated incompetent are emancipated and able to be considered their own person. How does this play out with informed consent for medical and dental procedures? The misinterpretation and misunderstanding of the use of restraints and restraining maneuvers to enable clinicians to treat people with developmental disabilities has scared off more dentists and physicians than all the issues of reimbursements. We need access to all the techniques employed in the pediatric and adult neurotypical population. We need to appreciate the concerns of the advocates, yet not curtail the clinician's armamentarium to get the job done with the best chance for successful outcomes.

We also need to:

1. remind physicians of the role of oral health in comprehensive health care;
2. emphasize the role of oral health in systemic disease management; and
3. work together to create partnerships that provide the best collaborative, comprehensive, coordinated, communicated, and compassionate health care available to patients with developmental disabilities.

The purpose of all of these endeavors, initiatives, and challenges is to finally demonstrate what brought us to where we are today: People who at a point in their lives decided that the best thing they could do in life was to announce their decision to become “doctors.”

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