Conference Paper

# A Look Back: Lessons in Family Activism and Recommendations to Address Today's Oral Health Challenges for Children with Special Health Care Needs

Betsy Anderson

**Abstract:** *The US Maternal and Child Health Bureau's Division of Services to Children With Special Health Care Needs has developed a national agenda for the development of systems of care of children with special health care needs. The purpose of this presentation was to discuss family activism in the care of children with special health care needs, and to explore the obstacles and successes encountered between the 1970s and today regarding: (1) family centered care; (2) provision of health care services; (3) availability of information for families; and (4) financing. Recommendations are presented concerning: (1) family centered care and partnerships; (2) care and services; (3) information and data; and (4) financing. (Pediatr Dent 2007;29:117-22)*

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Family activism and partnership with the federal Maternal and Child Health Bureau (MCHB), Rockville, Md, and other professionals has resulted in tremendous improvements in the programs, policies, and systems of care for children with special health care needs (CSHCN). Three points in particular stand out:

1. A national agenda has been created for the development of systems of care for CSHCN, Maternal and Child Health (Achieving and Measuring Success for Children with Special Health Care Needs by 2010: A 10 Year Action Plan. DHHS, HRSA, MCHB; Spring 2000).

2. Family centered, community-based, coordinated care has been included as language for the MCHB, Omnibus Budget Reconciliation Act (1989).

3. The Family Opportunity Act was passed, which provides for a number of important services, including Family-to-Family Health Information Centers (F2F HICs; 2006)

The MCHB's Division of Services to Children with Special Health Care Needs has developed a national agenda for the development of systems of care for CSHCN. This agenda includes 6 critical indicators of progress: (1) medical home; (2) insurance coverage; (3) screening; (4) organization of services; (5) family roles; and (6) transition to adulthood.

The agenda, with descriptions of the indicators, can be found on the Health and Human Services, Health Resources and Services Administration Web site. The agenda actually dates from 1989, the year the words "family centered, community-based, coordinated care" (cultural competence was added soon after) were included in the Omnibus Budget Reconciliation Act. The Family Opportunity Act, with strong bipartisan support, established F2F HICs in various states. This acknowledged both the needs of families of CSHCN and the strengths of families as providers and navigators of information for both families and others in today's complex health care systems.

How did we get to this point? How did this agenda and these centers come into being? I would like to take you along on the trip families have taken. When we began, few if any of us had heard of the MCHB and certainly could not have known the role this federal agency would play in the lives of our children—and our own lives as families.

Across the country, families were experiencing significant difficulties; it was becoming clear that the "system of care" for our CSHCN was at odds with our needs and expectations. What follows are highlights from our experience in the Boston, Mass. area—highlights of the obstacles, strategies, and successes we experienced, all of which contributed to the impetus for change. These experiences and activities were also mirrored and enrichedlarged by those of other families across the country. It was our great good fortune that, by the 1980s, the MCHB was ready to:

1. listen to families and professionals;
2. fund model programs; and
3. take the steps needed create the framework for a system of care for our children.

*Ms. Anderson is Director, Family Voices IMPACT, Boston, Mass.*
*Correspond with Ms. Anderson at banderson@familyvoices.org*

The first talk I ever gave to a dental group was in the early 1980s. There was a lot I did not know, both about dental issues and about my own role as a parent leader. At the end of the presentation, a man said, "I'm the handicapped dentist in my area. How can I get my colleagues to take on some of these children?" Although a bit taken aback by his terminology, it was obvious he was a champion for CSHCN. Another man insistently wanted to know what I could do to get Medicaid to reimburse a specific amount for filling cavities. Several thoughts filtered through my mind as he spoke. He equated CSHCN with Medicaid, but while some had Medicaid coverage, certainly not all did. I did not know about differential reimbursement rates, nor was I sure what my role could be in affecting this level of change. It was hard to imagine going to our Medicaid director and asking for a specific dollar amount for filling cavities. While the next sections will focus on the health system we encountered, I will come back to dental issues and the questions these 2 dentists posed, which are, unfortunately, still relevant today.

While it would have seemed presumptuous to have "an agenda," we families had many items on our minds. Being with our was key. In many hospitals we were limited to only 2 or 3 hours a day—which sent a definite message about our roles. Access to information was another goal, since little to no information, written or otherwise, was available to us. Also important was the chance to have real discussions about policies and programs—the kind of collegial opportunities such as we have here today at this conference. Achieving success for our own children was important, but additionally, we did not want other families to encounter the same barriers we had. We sought systemic change and felt we had a lot to contribute to the well-being of our children, both in terms of ideas and actual care. We also hoped for ongoing opportunities to interact and work collaboratively with professionals. Finally, we also needed vehicles for communication that would be ongoing and did not need to be developed from scratch in times of crisis. These and many other thoughts were on our minds.

## Family centered care

**Obstacles.** As families who were beginning to become active in our children's care, there was little to no role for us in the 1970s and, consequently, nowhere to go but up. We began our efforts with hospitals. When asked why he robbed banks, infamous bank robber Willie Sutton once said, "Because that's where the money is." Likewise, hospitals were largely where CSHCN were cared for; consequently, that is where our first efforts were focused.

**Strategies.** The strategies we used were numerous. We moved from the single disability approach—which had characterized most efforts for those with special health needs—to a broader rubric: CSHCN. This enabled us to address the program and policy issues that impacted many children and families, regardless of diagnosis. While we will always need single condition efforts, it is important to devise solutions that are appropriate for the times and issues being addressed. Our first involvements focused on hospital policies, particularly hospital visiting hours and space for us to be with our children. One organization, Children in Hospitals, based in Massachusetts, published the visiting policies of all the hospitals in our area. This was eye-opening for the hospitals and resulted in visiting hours increasing eventually to 24 hours. Often, we were told that the reason we could not stay with our children was due to lack of space

Though more difficult, we took advantage of state regulations required of hospitals as they built or renovated. We filed as 10 taxpayer groups. This made us the recipients of more paper than we ever imagined—every bit of correspondence imaginable between a hospital and the state! It also required the hospital to meet with us to listen to our concerns. Additionally, we became comfortable being labeled "problem parents;" the many support and advocacy groups formed at this time provided important reinforcement. Finally, we also used what we called "positive peer pressure": When one professional or setting did something we thought worked well, we tried our best to broadcast it to others. When one hospital began instituting sibling visiting hours, we brought a copy of the policy to other hospitals. Much professional literature at the time stigmatized both us and our children, typically capturing parents at the time of diagnosis without recognizing that families grow and develop. When we did come across articles that expressed what we felt were important ideas and viewpoints, however, we sent them to professionals. (This also encouraged some professionals to share journal articles with us, articles we would never have seen otherwise.) All along, we had support from professionals, but we needed to increase their numbers and create the kind of opportunities and atmosphere where they would be able to speak up publicly, as we were doing.

**Successes.** We believe that a key success in our quest was the formation of Family Voices in 1992, a national grassroots network of families and friends based in New Mexico. Family Voices supports health care services that are family centered, community-based, comprehensive, coordinated, and culturally competent for all CSHCN. It also promotes the inclusion of all families as decision makers at all levels of health care and supports essential partnerships between families and professionals.

By the end of the 1980s hospitals in the Boston area, beginning with tertiary care centers, no longer called parents "visitors" and allowed us to come at any time. Parent advisory committees were established at hospitals. Our views

had enlarged, and we were often successful in getting State Title V programs to include advisory committees, too. Family roles became recognized, not only for families in the care of their own children, but also in broader areas of program and policy. One of the most important outcomes, and key in effecting change, has been the support and encouragement to families in these roles now routinely offered by professionals —most notably MCHB's Division of Services to Children With Special Health Care Needs.

Family/professional partnerships now exist at all levels of care. Family members now: (1) provide advice; (2) contribute to research design; and (3) participate in the evaluation of services. Furthermore, hospitals, health departments, and even some practices now hire family members for their expertise. Family Voices' recent surveys of family participation with Title V MCH and CSHCN programs in all 50 states document this. Finally, to our amazement, family centered care and its siblings (patient-centered care, etc) are now used as selling points for hospitals and health plans.

## Care and services

**Obstacles.** Initially, when we began actively advocating for care for our children in the 1970s, we saw needs for many additional services for CSHCN and many gaps in care between providers and different service systems. There was also a lack of "parental presence" in hospitals and during medical tests and procedures. Later, each specialty "bloomed" and had recommendations for us. Early on, we felt we were viewed only as the transportation for our children. Later, it was realized that parents could provide care under professional direction. (One article extolled the virtues of using parents as caregivers who "constitute a cheap, continuous treatment resource…and work conveniently within the home.") Helen Featherstone's book, *A Difference in the Family*, however, showed that so much care was being placed in families' hands that, in her example, the extra tooth-brushing recommended for her son, Jody, was the straw that broke the camel's back. Where would she find that extra 20 minutes in a life already overfull with work, other family members, and a child who required total care?

Early in our efforts in the 1970s and early '80s there was little to coordinate; later by the late 1980s and '90s , it was recognized that care was fragmented and uncoordinated. Professionals simply did not work together or with families to establish plans and priorities. Virtually all care for CSHCN took place in specialty settings. Primary care providers did not feel comfortable or confident, and some were not even sure of the value of their roles. They were left out of the communication loop and did not know what other care was occurring for our children. Most had attended medical school at a time when children with serious disabilities often did not

live to be treated or were sent to institutions. Additionally, many of the treatments and procedures were brand new and, therefore, unfamiliar to all but those in specialty care.

The term "quality" was almost unspoken with families. The assumption was that the care our children were receiving was what they needed and was considered the best. Quality was something providers controlled. As families, we tried to achieve what we thought was the best care and services, but we were severely limited in our access to information.

**Strategies.** In the 1980s and '90s, families and professional allies actively worked to enlarge and legitimize the role for families, both in the care of our own children and also in program and policy areas, building on and adapting success in other areas.

Life-altering changes in special education occurred with the 1975 passage of the Individuals with Disabilities Education Act (IDEA)—the federal special education law. Built on civil rights concepts that "separate was not equal," these changes came about largely through the efforts of families and advocates; they did not happen from within. Although education was a different system that was regulated by law and in the public sector, the same children who had special education needs were largely the same children who had special health needs. New laws gave parents access to reports and information about children's needs. Moreover, it gave parents a role in planning services and signing off on individual education plans. These were important and useful models, and we did our best to bring them into health settings. These laws also created roles for families at other levels of the educational system, including state and federal advisory boards.

**Successes.** Considerable health care changes were occurring. Teams within hospitals had come into being, so that at least there was a fledgling way to share some of the information about a particular child. Additionally, a wave of innovation and attention to CSHCN resulted in new technology, techniques, and equipment.

An important outcome of families' efforts in the 1980s and 1990s to bring home children assisted by medical technology, largely seen as a financial issue, was the new perspective given to family provided care. For example, children on ventilators—who were routinely cared for in hospital intensive care units by highly skilled professionals—came home to be cared for by community nurses who needed training and by families themselves. It quickly became apparent that, due to the combination of funding gaps and home care schedules, families and growing children themselves needed to become expert providers of care. In turn, it was obvious that, if children with the most severe needs could be cared for at home by parents, so too could children with a variety of other, less intense needs.

## Information and data

**Obstacles.** Information for families was limited to nonexistent. The little information we could gain access to was not what would be called family friendly. Medical school and hospital libraries were generally closed to us. With many new support organizations forming, typically a first activity was to develop a pamphlet for families on a specific condition. But we were also missing other sorts of information—nothing was available about the procedures our children were undergoing, the resources available, or the care we were expected to provide at home. Adding insult to injury, in most cases we were not permitted to see our children's health records, but we were required to sign permission for others to do so.

**Strategies.** In some cases, state laws actually did give patients and families of minors the right to see medical records, even if hospitals and professionals routinely denied this access. Carrying letters detailing state medical records laws provided by a state's attorney general was one successful strategy. In other cases, families identified "unguarded" hospital libraries that were, therefore, somewhat accessible; material could not actually be borrowed, but at least it could be read.

**Successes.** Clearly, the Internet has had the single biggest impact on access to information, although the sheer volume of information presents problems of its own. Additionally, while families now have access to a world of knowledge, sorting out credible from unreliable sources is problematic.

National data sets, such as those available from the National Survey of CSHCN (2001) and the National Survey of Children's Health (2003), offer a wealth of information. Additionally, the Child and Adolescent Health Measurement Initiative (CAHMI) of the Oregon Health and Science University, Portland, Oregon, is funded to offer resources to assist in understanding and using the data, an important innovation—with families deemed a key user group. (Families also participated in devising these surveys and adding perspective to the findings.)

MCHB data—national and state performance measures—are easily available online. (Note that national performance measure no. 9 asks states to identify the number of third graders with dental sealants and that 37 states/territories have a state performance measure relating to oral health.) Here, too, the expectation now is that this information should be widely shared by a variety of partners, health professionals, and policymakers, with families firmly among them.

Finally, the Family Opportunity Act (FOA), passed in 2006, provides for the establishment of Family-to-Family Health Information Centers (F2Fs), recognizing that in the present health care climate, not only do families of CSHCN need information, but that it can best be provided by other families.

## Financing

**Obstacles.** Interestingly, financial issues were seldom if ever mentioned in the 1970s and '80s. This was a topic most health professionals were uncomfortable talking about. Today, as we know, the financing of health care and its health and economic consequences for the nation are topics of ongoing, open discussion. While there has certainly been progress, the overall lack of resolution is widely acknowledged.

**Strategies.** In the 1980s families began making financing issues a topic of discussion within family organizations and their newsletters—taking away the taboo nature of the subject. Open discussion removed much of the stigma, provided important information, and allowed many to openly discuss and advocate for changes.

Family organizations began to collect data, such as the number of calls their organizations receive relating to health care financing and the themes they addressed. For example, while legislators and professionals began to consider how many did or did not have health insurance, families knew early on that even those with health insurance still had substantial financial needs.

Perhaps one of the most effective strategies families employed was the use of family stories—vignettes that vividly and often wrenchingly brought issues to the attention of policymakers and payers. Later, in the 1990s, combining data with family stories proved particularly effective, and is the strategy of choice today.

**Successes.** The Katie Beckett waivers home and community waivers under Medicaid) became an option in 1982. While this began as an "exception to Medicaid" for a single child, it has now been passed into state regulations for thousands.

The State Children's Health Insurance Program (SCHIP), passed in 1997, emphasized the importance for all children to have health care insurance coverage, even if the country was not ready to provide it for all adults. SCHIP will be reauthorized later in 2007. Families and family organizations were actively involved in both the federal and state aspects of this legislation.

The Family Opportunity Act, passed in 2006, contains several sections that relate to improved health care financing, including options for states to offer Medicaid buy-in programs for families of CSHCN and waivers for children with serious mental health needs, similar to the Katie Beckett waivers.

While health care financing remains an enormous national challenge, one can be encouraged by how far the nation's knowledge has grown in terms of the awareness of problems. This may lead to more effective future resolution.

## Recommendations

The paper "Promoting the Oral Health of Children, Adolescents, and Adults with Special Needs Health Care Needs (April 2007, Association of State and Territorial Dental Directors, CSHCN Advisory Committee) has already taken the 6 elements discussed at the beginning of this paper and focused on them in terms of dental health. This is an important step in joining dental health goals and strategies to those of other health efforts for CSHCN.

Furthermore, a variety of initiatives now focuses attention on oral health, among them the:

1. National Maternal and Child Health Oral Health Resource Center;
2. Association of State and Territorial Dental Directors seed grants to states to hold oral health forums and develop state plans for dental health for CSHCN;
3. Children's Dental Health Project;
4. American Academy of Pediatrics; and
5. Special Olympics dental health program.

Turning to the four areas described earlier, the following are my recommendations regarding needs and next steps.

## Family centered care and partnerships

1. Extensive work on family centered care has occurred, since the 1980s, for health professionals and many others. Extend these activities to oral health. It is important to understand what family roles and support can mean on a variety of levels to the dental health community. At a Fall 2006 meeting sponsored by the Association of State and Territorial Dental Directors at which families, dental providers, advocates, and other members of the pediatric care community were present, a parent wrote, "These were not the usual participants. Dental providers had never been to meetings with us, they were not familiar with family centered care and the roles families can take to improve care and services."
2. See families as primary providers of care, especially preventive dental care, but also for much of their children's specialty care. Consider the information, support, reinforcement, and training needed by families to do these jobs effectively.
3. Consider a wide range of roles families can carry out on a variety of levels, beyond the care of their own children, such as being advisors to dental practices, providers of in-service education for practice staff, reviewers or writers of educational materials intended for families, reviewers and contributors of practice Web site information, participants in research design and review, speakers at conferences, and co-sponsors/testimony providers to support legislation intended to benefit the dental health of CSHCN. (In the fall of 2006, the American Academy of Pediatrics held a public, online review of the updated Bright Futures Guidelines. Family Voices encouraged families as well as young adults—Family Voices KASA [Kids As Self Advocates]—to participate. In one of the sections for professionals that offered possible questions to ask adolescents, a KASA member suggested, "Ask them if they like their smile.")

## Care and services

A needed challenge is to create a "virtual team" that brings together the many players involved in a child's care, all of whom have something to contribute as well as learn. Older children, families, dentists, primary care providers, specialty care providers, ancillary care providers, and perhaps special educators could all help to design and participate in more effective ways to manage a child's care.

Health and wellness should be more strongly emphasized for CSHCN. Threaded through the Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities (2005) is the concept of developing and maintaining healthy lifestyles for those with disabilities. Build on Medical Home/Dental Home and Bright Futures initiatives to encourage health and wellness in all aspects of care.

A variety of strategies should also be developed, not only for those who are already champions for dental health for CSHCN, but also for those dental providers who may be less sure what they have to offer. Consider and then design the kinds of information, training, and support needed by those in practice now. Do not let any dentist be the only "handicapped dentist" (even if we update the language). The present situation for the dental community seems much as it did for primary care providers in years past, when they received no information about a child's care and treatment from specialists and when they were effectively "out of the loop." Medical home education and information for primary care providers likely offers experiences and formats that would work for those in the dental community. Use what works and build in other elements as needed.

Furthermore, expect that quality is now on the minds of many families, whether spoken or unspoken. Share information about this topic and expect that some families will come to visits with information. Some of these families may be right on target, but others will benefit from discussion and clarification.

## Information and data

We should all participate and help shape national, state, and local health and dental health initiatives. Whenever possible, try to link these to broader efforts for children's overall health care.

Additionally, aim to provide more specific and acces-

sible data on dental health issues, such as financing. Provide easy access to information, such as rates of dental coverage for both insured and uninsured. While this information is presumably well known and understood by those within the dental community, it is not well known or publicized outside of it, unlike health insurance coverage, for which statistics are frequently publicized. Other financial information such as copays and out-of-pocket costs are similarly not well publicized to the advocates or the general public, nor are the strategies proposed to address them.

Use the new opportunities offered by states' Family-to-Family Health Information Centers. Ensure that quality information on dental health for CYSHCN is available, Ensure also that the dental health community is aware of the potential for resource dissemination and partnership. F2Fs also collect data on calls they receive.

## Financing

We also need to express and define financing issues in ways that others, beyond the dental community, can understand and support. Returning to the early plea from the dentist for increases in the amount paid by Medicaid for filling a cavity, try to frame financial issues in terms of children's health and needs, which naturally includes appropriate compensation for practitioners.

Work to put teeth and gums back into the child. Historically, the provision of dental health and dental health financing, notably insurance, has been separate from the rest of medical health. The original reasons for this need to be reexamined, along with the current impact on the delivery of and payment for oral health.

Work actively for good overall health for CSHCN. There is now a broad community of advocates, many of whom are very adept at understanding health care financing issues. These people and this knowledge can be more readily tapped if the dental community is seen as players in this bigger picture, not as advocates only for their own special interests.
Finally, strive to build a community of champions for dental health. Build on Bright Futures' concepts, such as:

1. Health promotion works;
2. Families matter;
3. Raising healthy children is everybody's business.