Could someone check to see how many of the people listed are coming to this meeting? They've all been invited,
Ignore those with a ✓.

Diane F.

FAMILY VOICES

Ciro V. Sumaya, M.D., M.P.H.T.M.
Administrator
Health Resources and Services Administration
Rockville, Maryland 20857

November 11, 1996

Dear Dr. Sumaya:

Your letter from several weeks ago has taken a prominent place on my desk. It reminds me that I must send you a response that reflects my gratitude for your understanding of the dilemma shared by so many families who have children with special health care needs. Your letter also makes it clear that there are many people, not all of them families and front-line health professionals, who also worry about the future of our children with special health care needs. Clearly, there is a heightened awareness about these children and the federal policy that guides services, programs, and the allocation of resources on their behalf.

It was heartening to read in your letter that HRSA's Maternal and Child Health Bureau (MCHB) supports families as partners and believes in the inclusion of our children in MCHB initiatives. We have seen such inclusion occurring recently within the MCHB in divisions beyond the Division of Services for Children with Special Health Care Needs (DSCSHCN), where such efforts were developed and nurtured over the years. It was also heartening to see that the MCHB chose to maintain the presence of the DSCSHCN in its reorganization. However, it appears to many of us that as the MCHB reorganizes, resources and programs are being taken from the Division and moved into other parts of the MCHB. As that occurs, we wonder how the MCHB will assure us that an adequate focus on children with special health care needs can be maintained and that policies and services for our children with special health care needs will have the attention and resources they require.

This may appear to be an arcane issue --- and one that families have historically not been involved in. If these were ordinary times, we families would be more than happy to leave the reshuffling of bureaucracies to others. However, on a daily basis, our children with special health care needs and their families face a number of crises. Increasing managed care mandates, decreasing employer-based health insurance, Medicaid cuts, Welfare Reform restrictions, and state budget cuts all impact our children and present families with an almost unbearable onslaught of change. Of all the times when we need a distinct, high profile "federal home" that will protect and develop good health policy for our children, it is now.

Therefore, it is important for Family Voices and our 10,000 member families to know if the DSCSHCN will continue to have the federal responsibility for providing a permanent, well-defined federal focus on this vulnerable population. And, if so, what assurances do we have that the DSCSHCN will have the resources it requires to fulfill that role?

Thank you so much for caring about our children and understanding why we families must be outspoken in our commitment to our children. By the way, I will be in Rockville on Monday, December 9. Would it be possible to meet with you then?

Sincerely,

Polly Arango

cc: Secretary Donna Shalala
Dr. Audrey Nora
Ms. Diana Fortuna

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

20-Nov-1996 11:21am

TO: FORTUNA_D

FROM: Richard J. Turman

CC: Nancy A. Min
CC: Barry T. Clendenin
CC: Chin-Chin Ip
CC: Wm G. White

SUBJECT: Re: 2 programs

Message Creation Date was at 20-NOV-1996 11:13:00

You had also asked about HRSA's "Division of Services to Children with Special Health Care Needs, which is part of the MCH bureau."

Two things:

1) states are required to use at least 30% of whatever they get from HRSA's MCH Block grant on children with special health care needs (Section 505(a)(3)(B) of the Social Security Act). The state portion of MCH goes up by $58 million under the proposed funding levels, so state funding for these children would go up.

2) as for HRSA's specific program office that consults with states on how states spend their 30% of the MCH block on such children (among other things), we don't have any particular number or proposal. We give HRSA one big number for their administrative operations (we've provided $101 million in FY98, down from $113 million in FY97 to reflect reduced administrative spending on health professions, Healthy Start, and other small HRSA grants), and let them spread it to this Division, as well as to all other Divisions and Bureaus. It would be very rare for us to indicate to HHS how much to give a particular sub-office of administrative types, because this would be intruding in a big way into the management flexibility of the MCH Bureau and of the Administrator of HRSA, Ciro Sumaya.

Give us a call with any further q's!

I have a 10:00 commitment
I'm late for - I apologize,

Children with Special Health Care Needs Meeting--Fri., Dec. 20--9:00-10:00 am--729G

Person	Position	Phone Number	Fax Number	
✓Polly Arango	Family Voices	(505) 867-2368	(505) 867-6517	
✓Julie Beckett	Family Voices	(319) 395-7349	(319) 395-7085	
✓Dr. Phil Lee	Asst. Secy. for Health	690-7694	690-6960	
✓Olivia Golden	Acting Asst. Secy. for the Admin. on Children & Families	401-2337	401-4678	YES
Cherry Tutsmith ~~(Dr. Ciro Sumaya)~~ Doug Lloyd	Health Resources and Services Administrator	(301) 443-2216	(301) 443-1246	NO ?
Doug Lloyd ✓Dr. Audrey Nora	Director, Maternal and Child Health Bureau	(301) 443-2170	(301) 443-1797	YES
✓Dr. Merle McPherson	Director, Services for Children with Special Health Care Needs Division	(301) 443-2350	(301) 443-1728	YES
Mary Beth Donahue	Deputy Chief of Staff	690-6133	690-7755	YES
Ann Rosewater	Deputy Asst. Secy. for Policy and External Affairs	690-7409	690-6562	YES
✓Joan Lombardi Mimi	Director, Child Care Div. of Children's Bureau	401-6947	690-5600	LEFT MSG.
✓Bob Williams	Commissioner, Policy, Plans, & Programs	690-5806	401-9507	LEFT MSG.
Carol Williams Linda Reese Smith	Deputy Commissioner, Policy, Plans, & Programs	205-8618	260-9345	CAROL WILL BE OFF; SHE'LL SEND SOMEONE + WILL CALL W/ INFO 12/19
✓Reginald Wells	Deputy Commissioner, Policy, Plans, & Programs	690-5806	690-7668	YES
Mary Clarkson ~~Sally Richardson~~	Deputy Admin., HCFA	690-6726	690-6262	YES
✓Connie Garner	DAS - Earl Fox - MCH	205-8124	205-9252	YES
Nancy-Ann Min	OMB	5-5178		LEFT MSG.
Richard Turman	OMB	5-4926		LEFT MSG.

✓FO Bouffard +1

Ruth Katz

Mimi - HRSA DSAS - Head Start

THE FEDERAL ROLE IN PROTECTING CHILDREN WITH SPECIAL HEALTH CARE NEEDS: A FAMILY PERSPECTIVE

The Problem: There is no consensus from the federal government about its role regarding policy, services, and resources for children with special health care needs (children with disabilities and/or chronic health conditions). In fact, the vagaries of federal policy for our children are symbolized by the absence of federal agreement on a working definition of "children with special health care needs". Absent a coherent federal policy, this sense of ambiguity about our children results in: confusion about leadership and a champion for these children and their families within the federal bureaucracy; no single program or source of expertise readily accessible to other government agencies or the general public, with a potential loss of research and data for these children; scattered programs that compete for attention, resources, expertise, and authority; unjustifiable duplication and overlapping efforts; and muddled messages floating down to state programs that receive federal health dollars for this population.* Without a federal focus that acknowledges and supports children with special health care needs, families will continue their frustrating dialogues about policy, data, definitions, services, and resources with federal agencies and bureaus that cannot respond appropriately. The bottom line for families is simple: Families want coordinated federal policies that will support them in their efforts to raise their children with special health care needs at home with the help of professionals and friends and neighbors in their communities.

Basic Issues:

1. We must develop a federal policy, based on a philosophy of care, that will eventually include all persons, of all ages, who have disabilities and chronic health conditions. That philosophy should emphasize decentralization of responsibility to family and community. But let us begin with a developmental approach, with children.

2. The primary purpose of any comprehensive system of services for children with disabilities or chronic health conditions should be to support and supplement what families are doing for their children. While this may seem obvious, moving the family to the center of the system would be revolutionary: the opposite of policies that guide Medicaid, for example.

3. The system should serve all children with special health care needs. The vast majority of children with special health care needs will need very little beyond what their families, health practitioners, and teachers are already providing, but the services and programs now available should continue to be protected and provided, with coordination between public and private providers a critical element. At present, we offer a great many services to a small percentage of children with special needs, and do nothing systematic for the majority. It should be noted that the services to these children are inconsistent, varying greatly by state, diagnosis, eligibility criteria, and availability of providers

4. The system should keep most of the responsibility for paying for care for children with special health care needs where it is now: with the private sector, families, and communities. Many government planners' view of systems of services for children with special health care needs is skewed: they focus only on children and families who need lots of expensive services paid for by state or federal funds. Most costs for most children, however, are paid by other sources, such as private health insurance, families, and local schools. Nothing should be done to displace these payers. On the other hand, families who need financial assistance should receive it promptly and without excessive hassle. Policies should clearly delineate who will pay for what, why, and how.

5. Children with special health care needs must be served as early in life as possible. During the transition to a comprehensive system, priority should be given to reaching young children, without reducing services for those youngsters already being served. One group of children, adolescents who must at some point move into adult systems of care, tend to be ignored at all levels and in most programs.

6. We must gather better data about all children with special health care needs, including information about children with mental illness, behavioral problems, and learning disabilities. Once we know who these children are, we must decide who will be served, in what ways, and what outcomes we should expect. Outcome-based research can support the identification of effective practices. And then a major effort must be made to disseminate those practices.

7. Improved coordination between schools, health providers, and families can lead to better integration of children with disabilities or chronic health conditions into every aspect of ordinary life. Government policy should support and encourage the formation of parent-professional teams, and encourage all appropriate agencies to work together to assist the family to raise their child.

How to Address the Basic Issues:

1. A broad based group of stakeholders/planners should come together to develop, review, or refine models for a comprehensive system of care for children with disabilities or chronic health conditions. They must agree to base their thinking on a family-centered philosophy of care and to participate in a consensus model of decision-making.

2. That group will need expert assistance to overcome conventional thinking about systems of care for children with special health care needs, such as: that services must be provided by government; that the institution is the norm; that all kids with disabilities are severely disabled; that only highly trained professionals can provide services; etc.

3. The group should agree on a common definition of children with special health care needs, leading to agreement on how many there are, where they are, what services they require, what those services cost, and who should pay for them.

As mentioned earlier, this will require assembling much better information about all children with special health care needs, including those with mental illness, behavioral problems, and learning disabilities.

4. The group should focus on outcomes at critically important milestones during childhood: What do we want for infants with or at risk for special health care needs and their families? What do our children need as they enter school? When they leave school as adults, what skills should they have? Given agreement on these issues, and stripped of conventional thinking, we can then begin to construct and understand coordinated, comprehensive, community-based, family-centered models likely to produce the desired outcomes.

5. As the outlines of the models emerge, an effort should be made to identify communities where the models are already in operation. Theoretical models should be modified by actual experience before costs are determined.

6. Costs of the models should then be determined.

7. If the cost is not reasonable, the model should be further modified or discarded. The group's work should not be considered done until one or more models have been found that yield the desired outcomes at a reasonable cost.

8. This is a reinventing, not a restructuring, effort. Relatively little time should be invested in figuring out how to make the children's SSI program more effective, or on how to integrate Medicaid and school services. The point is to start with the child, his or her family, the professionals that serve them, and others in their community, and build from there. Starting with existing agencies and programs almost guarantees getting stuck in conventional thinking.

9. **Let us repeat:** This will require a meeting of stakeholders, with an equal mix of policymakers, families, agency people, providers, and advocates at the federal level. The meeting must be well-designed, well-led, and substantive, sweeping everyone out of their conventional boxes and assuring them that there will be not only long-term vision, but practical outcomes that all stakeholders can use and implement immediately.

- Note: We acknowledge that there are several strong federal offices fighting for and guiding programs and policies for children with special health care needs. The most veteran office is the Division for Children with Special Health Care Needs (DCSHCN) in the Maternal and Child Health Bureau (MCHB), which has the longest and most specific legislated mandate to serve children with special health care needs. However, we understand that MCHB is undergoing internal structural changes which will have an unknown and perhaps questionable impact on the DCSHCN and its history of protecting our children.

Polly Arango -8/8/96

*Nora-higher level TAG?

12/20/96

Jan 25 + again in March Fam V

Beleaguered - eroding - private hlth care ins.

Arango - pre ICWA

JB - became part of system
- no data - hunt in bCR
- MA Tags
- Who is in chg?

→ Agree it's a problem: PA

JB: family - ctrd vs. family focused

PA: Model - families + professionals

McH - "locate + treat complexity" 1935
Koop again - tech-dep.
1989 - Agenda; rewrite MCH in Goals 2000
Part H
VAP's
Common vision
FICC
Big 3 - HA, SSI, IDEA plus HHS

Doug Lloyd - ϕ - what makes it wk?
- states moving →
Head Start gd model
Bob W - strengths, must build on; w/in culture 7 HHS, not OSERS
→ Nora - TAG w/ACF + HCFA * higher level TAG

Ann - Dom Violence - Steering Comm
- ex: discovered gap in training

Julie - families there

what goes wrong?
what's gd about div
integration vs integration

Connie? FICC
Joan?
Bob

Acknowl that HHS is a place that is not always family/user friendly

HCFA, Div, ACF (ACYF)
+
PHS
Ch Sur
Child Care
ASPE focus

focal pt + critical mass

FAMILY VOICES

To: Diana Fortuna

From: Polly Arango

About: Children with special health care needs

Date: August 8, 1996

Here is the paper I promised you so long ago. It is based on the thoughts I shared with you in written and verbal form in June. What took so long? Family Voices feels quite a responsibility for speaking on behalf of so many children and families. I shared my written thoughts, therefore, with several people, primarily the Family Voices staff, all of whom have different perspectives and experiences than I. They helped me make some changes to the body, and then I wrote a problem statement. There are so many changes facing our children and families --- welfare reform/SSI, Kennedy-Kassebaum, Title V/Children with Special Health Care Needs state program modifications, Medicaid cuts, omnipresent managed care. Now is the perfect opportunity to get a handle on responsibility and coordination in the federal programs meant to serve them.

I hope this is helpful. Julie Beckett and I will be in Washington on August 20-21 for a number of meetings and we would be happy to meet with you at your convenience. Several families will meet with MCHB's Dr. Audrey Nora at 9:00 a.m. on August 21, to talk about our concerns about the changing focus on children with special health care needs within the bureau. These are interesting times!

Thanks for your interest in our children and their future.

FAMILY VOICES

To: Diana Fortuna

From: Polly Arango

About: Meeting about children with special health care needs

Date: November 13, 1996

Just a note to make sure I am clear about the meeting in December regarding a federal focus for children with disabilities and chronic health conditions (children with special health care needs). The purpose would be to bring all the federal players together with two family leaders (Beckett and Arango) to discuss the problem we have when health policy for children with special needs does not have appropriate placement within the federal government. This would be a one day meeting to state and understand the problem and perhaps consider some solutions. The ripple effects of this issue have impacts on these children and their families that range from federal and state policy and allocation of resources to managed care, education, parental employment, even media coverage.

Those attending will likely include you, Bob Williams, Judy Heumann, Phil Lee, Ciro Sumaya, Merle McPherson, Ann Rosewater, Connie Garner, Joan Lombardi, Carol Williams. These are the dates when Julie and I absolutely cannot be there: December 3,4,6,9 (am and early pm OK),13. Sorry --- but those are all speaking engagements for one or both of us.

Also, you mentioned a later, larger meeting on this topic that would include foundations. Steve Somers of The Robert Wood Johnson Foundation recently hosted a meeting of eight foundations to discuss consumer involvement in health care (or maybe just managed care). I know that representatives from Casey, Packard, Kaiser were there ---perhaps Pew. You might want to call Steve at 609/279-0700 to see who else attended and if they indicated an interest in children's health issues.

One last thing. We are busy trying to find a marked-moderate SSI case --- not an easy task. In making inquiries, I realized another impact of new SSI regulations: The SSI eligibility definition is frequently used for eligibility for many, many programs beyond SSI. For example, in the absence of a better definition, Hawaii is planning to use the new SSI eligibility criteria to determine which infants with special needs get medical coverage through the carve out in managed care!

Hope to see you soon. Thanks for your time and concern

Merle McP — culture concern — spt for activ + focus

MCH Bureau Audrey Nora
HRSA Dr. Samayo (he)
PHS

cc Carol Rasco
Ken Apfel
FYI.
Coyne, Chesser, Colvin

To: Diana Fortuna
From: Polly Arango and Julie Beckett
Date: August 7, 1996
Subject:

Family Voices is in contact with a number of organizations interested in ensuring that the changes in the children's SSI program are carried out as smoothly as possible, and that, when the process is finished, all children who need services continue to receive the services they need.

In brief, the approach being discussed is:

- Negotiations with the Social Security Administration (SSA) to assist them to develop a program for reviewing children's eligibility that will work for both SSA and families.
- A massive outreach effort to ensure that families who receive an SSA notice understand the situation they face and the steps that they could take prior to their meeting with SSA staff. We have discussed involving a substantial number of AmeriCorps Volunteers in this effort.
- A group of trained physicians and mental health professionals in each state to consult with the families' treating physicians on documentation issues. Several national medical groups have expressed an interest in participating in this part of the effort.
- Support to families, particularly between the time the letter is received and the first meeting with SSA, provided by thousands of local parent support organizations.
- A very large group of volunteer attorneys (100,000 or more) willing to file an appeal for any child found ineligible on the basis of the existing file and/or any new documentation submitted. The attorneys will take each child as far as the new law permits with the understanding that some children, unfortunately, will be found ineligible.
- A second, much smaller group of physicians and attorneys that will work with each state to ensure that the state is prepared to serve, and in fact serves, any child found ineligible for SSI but still in need of services.

CLASP - in talking phase

The intent is not to challenge the changes, but to ensure that a) families understand and are prepared for whatever may happen when their child's eligibility is reviewed; b) as many children as possible—ideally, all children—are able to avail themselves of their right to a hearing before being dropped from the program; and c) in the end, all children who need services continue to receive them. Further, the intent is to carry out this effort at the community level, using, whenever possible, community-based organizations and volunteers.

We'd be happy to provide more information on this effort at your convenience.

8/21/96

SSI - Wkg w/ Acad Peds - does who work w/ CWD

- P+A's

1st wk of Oct → * HHS/advoc mtg w: ?? just kids? all?
Bruce
Peter
Nora + McPherson (+ Samaya)
BDD

* Dr Nora - call re systems

mid Sept. * Who @ SSA - call Judy to see if she has started

SSA mtg w/ F-V
Nachri
ACCH
Rhoda
Marty

SAMHSA? HRSA?

Dr Nora - MCHB - long mtg
Reorg - pull out Fed AIDS
- systems dev. - move it out
- bring grps together: DC
- Wash: mgd care
- families @ public health
Block grant - that works

To do - docs
- legal assistance
- non-Dr grps

* 2/28 - 3/2

Institute for Child Hlth Policy - Cebley - got SSA grant

Who @ HHS know: Bob W
Ruth K