FAMILY VOICES
OF THE DISTRICT OF COLUMBIA

Public Hearing on Surplus and Review of GHMSI
September 10, 2009
Department of Insurance, Securities and Banking
441 Judiciary Square, NW

TESTIMONY of

DOREEN D. HODGES

My name is Doreen Hodges, Proud Parent of two (2) children with special health care needs and/or disabilities. I am also the Executive Director of Family Voices of the District of Columbia Inc. and my testimony is presented on behalf of that organization.

Family Voices of the District of Columbia (Family Voices), is a local 501c3 grassroots organization, which is federally funded as the Family to Family Health Information Center by the Health Resources and Service Administration Maternal and Child Health Bureau.

Our organization is affiliated with the national Family Voices network whose mission is to "achieve family-centered care for all children and youth with special health care needs and or disabilities." Through our national network which represents 50,000 families of children with special health care needs, and Family to Family agencies in fifty states and the District of Columbia we provide families with tools to make informed decisions about services for their children, advocate for improved public and private policies, build partnerships among professionals and families and serve as a trusted resource for families on therapeutic and health care decisions.

1258 Pleasant Street, SE ‖ Washington, DC 20020
Toll Free: 1.888.373.6618 Office: 202.373.5564 Fax: 202.373.0063
www.familyvoicesofdc.org

FAMILY VOICES
OF THE DISTRICT OF COLUMBIA

Our local organization mission is to advocate for improved public and private policies, build partnerships among professionals and families and serve as a trusted resource for families on therapeutic and health care decisions.

Our guiding principles that outline the type of services we work toward in every state are:

Family Centered Care – Because families are at the center of a child's life, they must be equal partners in decision-making and all aspects of the child's care. Family-centered care is community-based, coordinated, culturally and linguistically competent and guided by what is best for each child and family.

- **Partnerships** – Family-centered care is based upon strong and effective family-professional relationships built within the context of families' and professionals' cultural values and practices to improve decision-making, enhance outcomes and assure quality;

- **Quality, access, affordability and acceptability** – Children with special needs deserve primary and specialty health care that is of high quality, affordable, within geographic reach and respectful of family and community culture;

- **Health systems that work for families and children** – Health policies and systems built on a foundation of family-centered, culturally competent and linguistically competent care must be the standard for all children;

- **Informed families/strong communities** – Like their peers, children with special needs deserve every opportunity to enjoy a happy and healthy childhood at home in their communities. Families equipped with reliable, accurate information about ways to support their child's health, education and social development will help them grow into productive adults as defined by their personal, family and community cultural beliefs and values;

- **Self-advocacy/empowerment** – When informed and supported, young people with disabilities can make choices and advocate for themselves.

1258 Pleasant Street, SE | Washington, DC 20020
Toll Free: 1.888.373.6618 Office: 202.373.5564 Fax: 202.373.0063
www.familyvoicesofdc.org

It is our understanding from the DC Appleseed's analysis that CareFirst may have an excess surplus of about $300 million and the hope is that CareFirst and DISB will consider reinvesting its surplus dollars to meet some community health needs.

I would like to talk about some of the unmet health needs of District residents. I hope that CareFirst and DISB will consider reinvesting its surplus dollars to meet these community needs.

Just a little background on our organization's advocacy; back in 2006 Family Voices of the District of Columbia participated with Autism Speaks and other professionals and organizations with presenting draft legislation to the DC Council regarding Bill 16-711 entitled the "Rehabilitative Services Act".

Many of the Family Voices members including myself have children with extensive medical needs that are only partially covered by their health insurance.

This bill covered services such as Physical Therapy, Occupational Therapy and Speech and Language Therapy for children diagnosed with special health care needs and/or disabilities such as Autism, Down Syndrome, Cerebral Palsy and other genetic disorders to be able to receive the equivalent/same services as another peer who may not have been born and/or diagnosed with a special needs diagnosis. The limit is 60 visits.

The Bill passed, became Law and now governs all DC Insurance providers. Much of this law helped the local DC Employees, but leaves the Federal employees with a financial strain due to some of the examples I will outline below.

Example 1:

When the family receives the treatment of services to be rendered to the child and/or youth with special health care needs and/or disabilities it may be written for Physical, Occupational and/or Speech and Language Therapies at 3xs a week. The co-payment rate of $15-$20 per visit totals a weekly expense of about $45-$60. The monthly expenses coupled with the monthly premium could be about $500.

1258 Pleasant Street, SE | Washington, DC 20020
Toll Free: 1.888.373.6618 Office: 202.373.5564 Fax: 202.373.0063
www.familyvoicesofdc.org

Then it is multiplied for the 4-5 months; the cost would be about $2,000-$2,500. Remember this is only good for 4-5 months. If the child is recommended to have additional services, the families could be facing an out-of-pocket expense of an additional $14,000. The families could appeal for additional services deemed a "medical necessity" but that is no guarantee that they will be granted reimbursement of the additional expenses incurred.

Example 2: ABA and Psychological services (Neurological vs. Developmental Delays)

With the frequency rate of children being diagnosed with Autism Spectrum Disorder estimated at 1 child diagnosed with autism every 20 minutes or 1 out of 150 children. Researched-based services known as Applied Behavior Analysis costs anywhere from $5,000-$10,000 MONTHLY, depending on frequency of services to be rendered. CareFirst does not cover this service in any of their health care packages to families of children and/or youth with special health care needs. These services are deemed as a "medical necessity"

Psychological services such as evaluations, assessments for children and youth with special health care needs and/or disabilities classified as "developmental delays" are also a proven research based service to determine a child and/or youth's deficits. But again they not covered under CareFirst healthcare package plans. The District of Columbia has experienced a shortage of contract providers over the years and families are often left without DC Government provided services and families have to pay the costs out of pocket. Sometimes it is due to a wording technicality as simply being classified as a Psycho-ed. Which CareFirst believes would fall under the responsibility of the educational system.

Monies from the CareFirst surplus could be invested back into the community under a **Catastrophic Health Fund**.

Catastrophic Relief funds have been established in states such as Massachusetts, Connecticut and New Jersey many of these states are where you find similar demographics and analysis as the District of Columbia and surrounding states.

The Catastrophic Illness in Children Relief Fund (CICRF) helps families bear the excessive financial burdens associated with the care of children with special health care needs and disabilities. CICRF is a payer of last resort. It provides financial assistance for families with children experiencing a medical condition requiring services that are not covered by a private insurer, federal or state assistance, or any other financial source.

1258 Pleasant Street, SE | Washington, DC 20020
Toll Free: 1.888.373.6618 Office: 202.373.5564 Fax: 202.373.0063
www.familyvoicesofdc.org

The Fund is designed to act as a safety net for families who have excessive expenses related to a child's medical needs. The family may be responsible for these expenses due to:

- A lack of insurance or dependent coverage
- Expenses that are greater than the maximum benefit allowed by their insurance company
- Pre-existing conditions, co-payments, and other expenses that are not covered by insurance

In most of the states noted above their CICRF receives monies through an annual allotment of $1 for each employee whose wages are counted as part of employer contributions for unemployment health insurance. The State Treasury manages the Fund

This would be a win situation to families who do not have Medicaid or coverage through an employer; they face very steep prices on the individual market or are turned down altogether. CareFirst should make prices for its open enrollment and HIPAA products affordable.

This could be one way monies could be used since the District of Columbia does not have any waivers that serve children and youth with special health care needs and/or disabilities.

Example 2: Recreational Activities

Many of the organizations that CareFirst funds do not have inclusive settings, to include children and youth with special health care needs and/or disabilities. This is another area that could be funded. These activities could assist, enable and enhance all children with their development, prevention of obesity, health promotion and nutrition.

I want to thank you for the opportunity today and welcome any questions or concerns, but most importantly, I look forward to working with many of you on possibilities for the future.

Submitted by;

Doreen Hodges;
Executive Director
Family Voices of the District of Columbia
1258 Pleasant Street SE
Washington, DC 20020