

FAMILY  VOICES[®]
*...keeping families at the center
of children's health care*

ANNUAL REPORT
2009-2010





OUR MISSION

FamilyVoices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

OUR VISION

Every child and youth with special needs receives family-centered care.

Dear Friends,

Four years ago, FamilyVoices created a strategic plan to support our mission to achieve family-centered care for all children and youth with special health care needs and/or disabilities. This past year we continued to follow our strategic plan's directives by focusing on Policy, Cultural Competence, Infrastructure, and Funding. As the 2008-2011 strategic plan comes to a close, we are celebrating our accomplishments and preparing for our next strategic planning session to take place summer 2011.

In fiscal year 2009-2010, we hired two Policy Co-Directors, Janis Guerney Esq. and Brooke Lehmann Esq., both of whom are based out of Washington, D.C., to head our efforts to influence public policy and ensure that health care reform benefits our children and youth with special health care needs and disabilities. We will continue to work with our network to ensure that our elected officials and policy makers are informed about the importance of the Affordable Care Act to our families and their children.

We also continued our work to secure federal funding for the Family-to-Family Health Information Centers (F2F HICs) so that in every state, families have a local resource to find quality health care, services and supports for their children. Since launching the state-based affiliate membership structure in 2009, as of December 10, 2010 we have a total of 29 State Affiliate Organizations (SAO). We provide technical assistance to the F2FHICs and SAOs through the National Center for Family/Professional Partnerships grant.

Two of our FamilyVoices projects are highlighted in this annual report. The IMPACT project Bright Futures: Families First continues to be a wealth of information for families and professional partners, with

the American Academy of Pediatrics posting our newsletter on their Bright Futures website. Kids as Self Advocates (KASA) also continues to break ground by promoting self determination and advocacy skills to youth with disabilities.

We thank you for your support of our shared mission to keep families at the center of children's health care. We would appreciate your continued support toward realizing our vision that every child and youth with special health care needs receives family-centered care, related services, and supports.

With warm regards,



Ruth R. Walden
President, Board of Directors



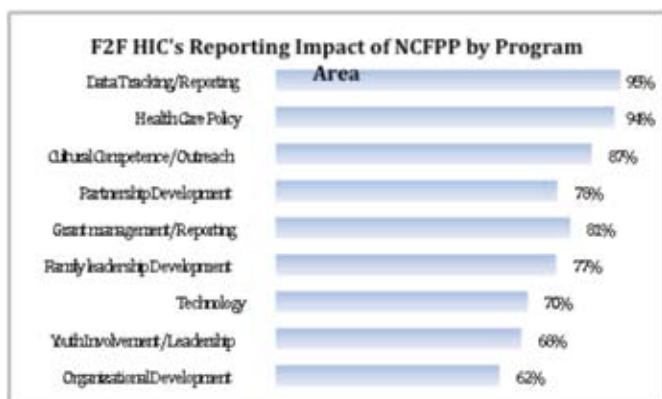
Sophie Arao-Nguyen, PhD
Executive Director



PROVIDING LEADERSHIP ON FAMILY/PROFESSIONAL PARTNERSHIPS

In our fifth year as the **National Center for Family/Professional Partnerships (NCFPP)**, a cooperative agreement with the Maternal and Child Health Bureau, FamilyVoices continued to provide leadership on effective family/professional partnerships for achieving family-centered care. Under this agreement, the NCFPP Technical Assistance Team, Policy Team, and National and Regional Field Coordinators have worked closely to:

Provide Technical Assistance to Family-to-Family Health Information Centers (F2F HICs) and family leaders through individualized assistance, trainings and regional conferences, and opportunities for peer networking in specific areas such as family leadership, cultural competence, public policy advocacy, organizational development, and grant management. From June 2009 through March 2010, the NCFPP responded to 767 requests for technical assistance and provided training opportunities to 4,064 families, family leaders, and professionals through 56 presentations/conferences/meetings.

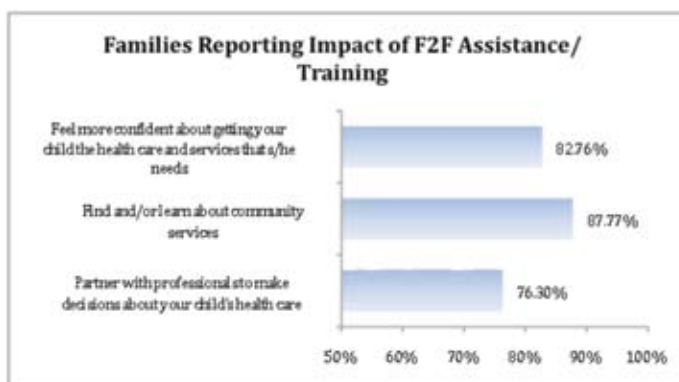


Inform families, family leaders, and professionals with resources and materials to enhance the understanding and practice of partnerships. In addition to monthly editions of *Friday's Child* newsletter and weekly Washington Updates, new



publications included the Annual F2F HIC Data Report, Customizable State Data Reports, Information on CYSHCN and Health Care Reform and the KASA Paraprofessional Toolkit.

Partner with the National Centers such as the National Center on Cultural Competence in a Community of Learners —“Share Family Wisdom.” Through this initiative F2Fs have come together to share their wisdom on creating and sustaining relationships with tribal communities. Participants engage in regular conference calls/ webinars, exploring approaches that build and enhance their relationships with Native American and Alaskan Native families and discussing strategies for sharing this wisdom with others.



Document evidence of family/professional partnerships and family-centered care. F2F HICs collect impact data from the families that they serve to identify how the help provided increases family confidence, information and opportunity to partner with providers. Examples of promising practices from F2F HICs are highlighted in *Friday's Child* and in the publications of partners such as the *American Academy of Pediatrics Council on Children with Disabilities Newsletter* and will soon be posted to the FamilyVoices website.

MEETING NEEDS FAMILY-TO-FAMILY

... BY PROVIDING TRAINING, INFORMATION AND RESOURCES

FamilyVoices of Wisconsin, the WI F2F HIC reports: *“Our foundation training, the ‘Did You Know, Now You Know’ curriculum is broadly sought by parents and professionals. We produced a webcast based on this training for new Birth-3 and children’s state program staff. We are a valued partner in Wisconsin around parent leadership initiatives for CYSHCN. Families are better informed and advocate more successfully for their children’s needs as a result of the work of FV of WI. Co-Director Liz Hecht chairs the statewide policy committee on children’s long term supports; Co-Director Barbara Katz was selected as a participant in the MCH-PHLI first cohort, and is the vice-chair of Wisconsin’s Board for People with Developmental Disabilities.”*

... BY PROVIDING INDIVIDUAL AND FAMILY SUPPORT

Leeann and her son.



Dina Castro is a Family Support Navigator with **FamilyVoices of Colorado, the CO F2F HIC**. In her position, she helps parents advocate for their children and provides resources and tips for navigating healthcare and educational systems.

This past year she attended

an IEP on behalf of one of her clients and was successful in getting individual accommodations included in the IEP, after 2 years of the school refusing to adequately address the child’s medical and mental health needs. The mother, Leeann, could not be more pleased with the outcome and had this to say: “I don’t know if you realize all that you have given me: Understanding, peace of mind, support, comfort, validation, knowledge/information, and the benefit of all your wisdom and experience. I feel so very blessed to have crossed paths with you in my life!”



FamilyVoices of Ohio employee Jennifer Wolford meets with Tara and her children to find community resources and to apply for SSI for her oldest child, who has autism.

When a parent contacts **FamilyVoices of Ohio, the OH F2F HIC**, they are often feeling overwhelmed with the stress of caring for a child with special needs. Parents of CYSHCN must often struggle with finding and maintaining employment while caring for their children. Jennifer Wolford works with these families to obtain services, find local resources such as child care, and to help parents get organized so that they can manage their daily lives more effectively. Jennifer also acts as a confidante to these parents who often need someone to talk to who can relate to their struggles, and is proud of the relationships she has forged with the families she helps.

By the Numbers

In its role as Technical Assistance provider to the Family-to-Family Health Information Centers, FamilyVoices aggregates data from each center and promotes their accomplishments through reports and newsletters. Between June 1, 2009 through May 31, 2010 F2F HICs reported:

INDIVIDUAL ASSISTANCE: Responded to over 250,000 requests for assistance from almost 90,000 families and 33,000 professionals.

TRAININGS/MEETINGS: Trained 171,545 families and professionals and participated in 11,391 meetings.

LISTSERVS: Reached 329,586 families and professionals through listservs and 709,255 families and professionals through newsletters.

PUBLICATIONS: Disseminated over 1.27 million fact sheets, guidebooks, brochures and other materials;

ONLINE: Recorded 19,476,365 web hits.

2009-2010 FISCAL YEAR HIGHLIGHTS

Mobilizing to Impact Policy and Secure Funding

FamilyVoices continued its work to support health care reform by developing and signing on to letters to congressional leaders, attending coalition and partnership meetings, and meeting with congressional staff to help ensure that the needs of children with special health care needs/disabilities and their families were considered and supported in the historic health care reform legislation.



Family leaders and advocates visit Capitol Hill.
From left to right: Janis Guerney, Mary Baskar, Vijay Baskar, Kelly Meissner, and Ashley Meissner.

Additionally, with the assistance of the network's grassroots, we were successful in getting a provision in the health care reform law that will fund Family-to-Family Health Information Centers (F2F HICs) for another two years (through federal fiscal year 2012). F2F HICs are statewide, family-led information and referral centers that help families of children with special health care needs in navigating the health care system.

Honoring Family Leaders & Professional Partners

The Polly Arango Memorial Fund was established after donations started flooding in upon the sudden, unexpected passing of our founding Executive Director. The Polly Arango Memorial Fund will be used to support an effort Polly modeled – a mentoring program for emerging family leaders – to help ensure the continuity of the family movement. Please visit our website at: www.familyvoices.org for more information.



The power of Polly's words, both spoken and written, will remain with us:

"Let us remember as each of us makes decisions that will affect children-whether we are parents, educators, health professionals, or government officials- it is our duty to consider if that decision either affirms or denies a child's most basic human rights." - Polly Arango

In October 2009 FamilyVoices Board Member Merle McPherson, MD, received the Arnold Capute Award at the American Academy of Pediatrics National Conference & Exhibition. This prestigious award is presented annually, to recognize a physician who has made notable contributions to the health and well-being of children with disabilities through service and/or advocacy at the local, state or national level. Merle plans to continue her work towards the implementation of a model of family-centered, culturally competent, community-based comprehensive care. Her ultimate goal is to expand and strengthen the health care service system for all children and their families so that it is universal, equitable and sustainable. Congratulations Merle!



FAMILY VOICES' PROJECT HIGHLIGHTS

Creating Bright and Healthy Futures for Families



Bright Futures for Families is a national initiative for families and communities to promote and improve the health and well-being of children of all ages. We offer resources for families based on the award winning, federally supported Bright Futures initiative, developed through the support of public health, non-profit, and corporate organizations.

Our children with special health care needs and disabilities are also part of the wider world of children – and we don't want families to miss out on any important resources or ideas. With an



The Bright Futures Team, pictured from left to right: Melissa Vickers, Barbara Popper, Beth Dworetzky, Bev Baker-Ajene, Betsy Anderson

Improving Understanding of MCH grant, Family Voices works to encourage partnerships between families and professionals for children's good health. Bright Futures: Family Matters, our free, electronic newsletter, is a publication to share with family and professional networks. In it we address children's health and wellbeing, using the 10 Bright Futures Themes: Child Development, Family Support, Healthy Eating, Healthy Weight, Physical Activity,



KASA board member Mallory Cyr attended the annual meeting of Association of Maternal and Child Health Programs (AMCHP) and visited Capitol Hill to meet with her state Senator Susan Collins. Says Mallory of the experience: "Seeing how things happen at a higher level really made the thought of making a difference seem real! Overall it was a great experience, and I can't wait to go back to DC and continue to strive for change!"

Oral Health, Mental Health, Safety, Healthy Sexuality, and Community Resources and Relationships. Each issue addresses a theme area, offers resources and tips, shares information about a partner organization, and includes current research that families are likely to find interesting and useful. Issues are available in Spanish. For more information visit us at <http://www.brightfuturesforfamilies.org>.

Paving the Way for Disabled Youth and their Adult Allies

Kids As Self Advocates (KASA) is a national, grassroots project created by youth with disabilities for youth. We are teens and young adults with disabilities speaking out. KASA knows youth can make choices and advocate for themselves if they have the information and support they need. We continued our work to support youth leaders in our communities by providing over 60 youth-written tip sheets and resource guides on our website www.fvkasa.org. We also strive to help health care professionals, policymakers and other adults in our communities understand what it is like to live our lives by developing resources such as the *Paraprofessional Toolkit: Working with a One-on-One Aide in School* to provide guidance to successfully work with a Paraprofessional in a school setting.

FAMILY VOICES
STATEMENTS OF FINANCIAL POSITION
June 30, 2010 and 2009

ASSETS

	2010	2009
Current Assets		
Cash and cash equivalents	\$ 313,361	400,215
Grants and contracts receivable	147,218	163,678
Other current assets	14,113	8,218
Total current assets	<u>474,692</u>	<u>572,111</u>
Equipment and Improvements		
Office equipment	42,509	34,606
Leasehold improvements	22,964	22,964
	<u>65,473</u>	<u>57,570</u>
Accumulated depreciation	(49,900)	(47,052)
Net equipment	<u>15,573</u>	<u>10,518</u>
Total assets	<u><u>\$ 490,265</u></u>	<u><u>582,629</u></u>

LIABILITIES AND NET ASSETS

Current Liabilities		
Accounts payable	\$ 21,474	42,049
Accrued liabilities	57,762	58,698
Total current liabilities	<u>79,236</u>	<u>100,747</u>
Commitment and Contingencies		
Net assets		
Unrestricted	398,396	464,394
Temporarily restricted, KASA	12,633	17,488
	<u>411,029</u>	<u>481,882</u>
Total liabilities and net assets	<u><u>\$ 490,265</u></u>	<u><u>582,629</u></u>

See Notes to Financial Statements.

BOARD OF DIRECTORS

From left:

Sue Sherry, Renee Turchi,
Scott Suzuki, Ruth Walden,
Grace Williams, Rachel Rodriguez,
John Foley, Wendy Jones,
Joan Christopher



FAMILY VOICES STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS Years Ended June 30, 2010 and 2009

	2010	2009
UNRESTRICTED		
Public Support		
Grants and contracts	\$ 996,162	1,152,218
Fundraising	475	135,910
Contributions	14,553	6,241
Interest and other income	12,927	7,715
Net assets released from restrictions	17,170	9,920
Total revenues	1,041,287	1,312,004
Expenses		
Community awareness	994,655	940,489
Management and general	98,438	225,950
Fundraising	14,192	72,520
Total expenses	1,107,285	1,238,959
Change in unrestricted net assets	(65,998)	73,045
TEMPORARILY RESTRICTED		
Contributions	12,315	25,370
Release of restrictions	(17,170)	(9,920)
Change in temporarily restricted net assets	(4,855)	15,450
Change in total net assets	(70,853)	88,495
Net assets at beginning of year	481,882	393,387
Net assets at end of year	\$ 411,029	481,882

See Notes to Financial Statements.

CONTRIBUTORS

\$1,000 – \$4,999

Sophie Arao-Nguyen, PhD
Colorado Springs Citivan Club (Verlene Betzen)
Margaret Mary Richards, PhD
Sue Sherry

\$500 – \$999

John & Polly Arango
Association of Maternal and
Child Health Programs
Nymia Cucueco
Mike & Peggy Curran
Yoshiko Dart
John W. Ellis
Rachel & Julio Rodriguez
Josie Woll

\$200 – \$499

Adelamar Alcantara, PhD
About Special Kids (Rebecca Kirby)
Kathleen Kirk Bishop
Maureen Bisognano
Van & Jeannette Coble
John Foley
Tawara Goode, MA
Doreen Hodges
Theodore Jojola, PhD
Dennis Kuo, MD
Edwin & Debra Langhenry
Lucile Packard Foundation
New Hampshire FamilyVoices
Marcia O'Malley
Personal Assistance Services of Colorado
(Barry Rosenberg)
PEAL Center
Tom & Linda Riley
Joseph Romano
Mikiko Stebbing
Mr. & Mrs. William Swaim
Bill & Becky Tallman
Jean Trainor

\$200 – \$499

BJ Voelkel
Grace Williams

\$100 – \$199

Wilfred Lee & Marcia Antigua, MDS
Karen Anzola, MEd
Association of University Centers on Disabilities
John & Kelly Bunnell
Donna DeBruhl-Hemer
Pat Egan
Kathleen Egan
Eileen Elias
Envisions IT (Kevin Gray)
FamilyVoices of Alabama
FamilyVoices of South Dakota
FamilyVoices of North Dakota
FamilyVoices of Wisconsin
Jay & Ellen Hardin
Ruth Hill, PhD
Lisa Hoffman
Martha-Jean & Robert Madison
Merle McPherson, MD
Missouri Bureau of Special Health Care Needs
Monica Niess
Sanjay Patel
Parents Helping Parents of Wyoming
The Pola-Money Family
PTI Nebraska
Pueblo Emergency Connections
Kip & Ruth Queathem
Scott Suzuki, Esq.
Statewide Parent Advocacy Network – New Jersey
Jana Stanfield
Josie Thomas
Brad Thompson
Nora Wells, MA
Fredericka Wolman

\$50 – \$99

Javier Aceves, MD
Sara S. Bachman, PhD
Missi Baranko
James Bryant, MD
Paige & Richard Cantwell
Janet & George Devito
M. Ann Drum, DDS, MPH
Pearl Feldman & Janice Fialka

\$50 – \$99

Richard Feldman
Herbert Fellguth
Debbie Gilmer
Carolyn Gleason
Janis Guerney, Esq.
Bernard Guyer
Marjorie Hardin
Albert C. Hergenroeder, MD
Judy Heumann
Cathy Higgitt
Nancy Holder
Jorge Pineda
Lacey Keene
Audie & Cubby Keene
Paul Kurtain, MD
Mary Marin
Aviva Must
Katherine O'Reilly
James Perrin, MD
Rick Rader, MD
Deanna Sands
Mary Castro Summers
Support for Families of Children with Disabilities
Fan Tait, MD
The Parents' Place of Maryland
Jennifer Thomas
Janice Underwood
Kay Van Woert
Dawn Wardyga

< \$50

Becky Adelman
Lauren Agoratus
The Arango Family
Helen Badoyannis
Sharman Davis Barrett
Julie Beckett, MA
Steven & Lillian Gonzales Brown
Sam Bryant
Leigh Carlson-Hernandez
Maureen Casey
Mary Castro Summers
Joan Christopher, Esq.
Jamila Davey
Augusta Davis

< \$50

Juno Duenas
Linda Dunagan
Beth Dworetzky
Carl Erickson
Family Voices of Oregon
Sue Fager
Rodney Farley
Julie Finholm
Sondra Gilbert
Beth Goodman
Georgette Guerra
Connie Hawkins
Joyce Hooker
Ahmed Ismael
Lynn James
Delores G. Jessie
Cassie Johnston
Wendy Jones, MSW
Richard E. Kreipe, MD
Brooke Lehmann, Esq.
Holly Lu
Adelita Martinez
Gail McGuire
Maureen Mitchell
Terry Ohlson-Martin
Nancy Pedro
Barbara Popper
Jim Potter
Florence & Octave Poyadue
Conant Rees
Veronica Rosales
Linda Rowley
Vella Salazar
Martha Simms
Grace Sisco
Jacqueline Steingold
Julie Sullivan
Trish Thomas
Renee Turchi, MD
Douglas & Kathleen Twite
Melissa Vickers
Ruth Walden
Wendy Ward
Macksi Warner
Tinya White-Taylor



ADD YOUR VOICE

Add your voice to help get the word out to more families, reach out to new partners, and provide extended support to the Family Voices network of family and youth leaders across the country. Together we can impact the lives of families with children and youth with special health care needs and disabilities!

- Donate online, by mail, or by phone
- Donate in-kind items or services
- Purchase Amazon.com products

Visit www.familyvoices.org or contact Rachel at rrodriguez@familyvoices.org for more information.

