



Legislative Victories in Challenging Times

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Presenters





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To encourage family organizations to engage in public policy advocacy

To share information & strategies for family organizations to engage in effective & successful public policy advocacy strategies in challenging times

Agenda



- Welcome
- Introduction to Family Voices and National PLACE
- 3. Overview of F2F funding process, history
- 4. 2017-18 efforts to extend F2F funding and expand program for territories and tribes
- 5. Key Lessons
- 6. Q & A

About National PLACE



Mission

 To educate and empower families and family-led organizations and support them to advocate for enhanced parent involvement and leadership in education, health and human services decision-making with regard to services for children and families.

Motto

 Advocating to ensure the parents' PLACE at decisionmaking tables

Members

60 national, state, and local family-led organizations



About Family Voices



Family Voices (FV) is a national, family-led organization of families of children and youth with special health care needs (CYSHCN) and disabilities. We:

- Connect a nationwide network of family organizations that support families.
- Promote partnerships with families at all levels of health care from individual health care providers to local, state, and federal policy-makers.
- Advocate for federal laws and regulations that will benefit CYSHCN and their families & help state organizations and families build their advocacy skills.

Through a federal cooperative agreement Family Voices provides technical assistance to the nation's 59 **Family-to-Family Health Information Centers (F2Fs)**. Family Voices has **State-Affiliate Organizations (SAOs)** in 42 states, 93% of which are also F2F grantees.

Family-to-Family Health Information Centers (F2Fs)



- Information and referral centers
- Staffed by families of CYSHCN
- Help families of children with special health care needs (CYSHCN) --
 - Navigate the health care system, and
 - Advocate for their children and for improved health care systems.
 - Work with health professionals to promote "familycentered" care.

Family-to-Family Health Information Centers (F2Fs)



- One F2F in each state and DC.
- Newly funded F2Fs:
 - One in each of 5 US territories.
 - 3 to serve tribal families.
- Each F2F receives a federal grant of less than \$100,000 per year.
- Work together nationally through FV National Center for Family Professional Partnerships (NCFPP)

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1999-2006

- Family Voices piloted models for F2Fs in all states and DC.
- Funded by the Robert Wood Johnson
 Foundation, Maternal Child Health Bureau,
 Centers for Medicare and Medicaid
 Services.



1999-2006

Family Voices vigorously lobbied both sides of the aisle to develop legislation that would provide federal funding for F2Fs.

2006 (at last!) -- A federal F2F grant program was created via the Family Opportunity Act (FOA), part of the Deficit Reduction Act.



How was this achieved?

Bi-partisan support was crucial –

- Champions:
 - Senator Edward Kennedy (D-MA)
 - Senator Chuck Grassley (R-IA).

Family leaders had built **relationships** with these Senators and their staffers over past years.

Sen. Grassley was chairman of key committee (Finance).



FY 2009

Each state and DC had an F2F grant (less than \$100,000 each)

BUT....

One catch -- the law did not authorize or fund F2F grants beyond 2009.



2010

F2Fs got 3 more years of level funding – through 2012 – via the Affordable Care Act (ACA).

How did that happen?



Once again, success depended on:

Support of champions (already cultivated by SPAN Parent Advocacy Network, NJ F2F grantee):

- NJ Dem. Rep. **Frank Pallone**, then-chairman of key House subcommittee.
- NJ Dem. Sen. Robert **Menendez**, on key committee.

And New Mexico Dem. Sen. Jeff **Bingaman** - represented FV founder and headquarters; on key committee. **PLUS...**



Bipartisan support - Sen. Grassley also on committee (no longer chairman)

Vigorous advocacy by family organizations, family leaders, FV staff

Nature of program and request:

- -very low cost
- history of bipartisan support
- no changes to text of law (not asking for more \$)
- noncontroversial, sympathetic cause



FYs 2013-2017:

Four different laws provided level F2F funding lasting through FY 2017.

Once again, success depended on:

- advocacy by family organizations & family leaders
- relationships with Members and staff
- bipartisan support
- "flying under the radar" (low cost; no more \$)

General Pathway of Proposals

- Most small bills or provisions (like F2F extension)
 need a legislative "vehicle" (larger bill) on which
 they can "travel," preferably one that is very
 popular or a "must-pass" bill.
- Committee chair drafts a bill ("chairman's mark") for the committee to consider in a "mark-up."
- Chair often consults committee's "Ranking Member" in developing the mark.

Pathway of Proposals (cont.)



Chairs and Ranking Members want to please their party's committee members, so...

Advocates identify **champion(s)** who are:

- on committee of jurisdiction
- from the majority party or from both parties
- ideally in House and Senate.

A **champion** is a Member who is willing to devote staff time and use political capital to get provision enacted.

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Pathway of Proposals (cont.)



 Champion(s) may introduce a bill to spell out the proposal if confident of getting enough cosponsors, preferably bipartisan.

 Champion(s) ask committee chairman and/or ranking minority-party member (whoever is of champion's party) to include the provision in the chairman's "mark" of relevant legislation.

Pathway of Proposals (cont.)



Lobbying occurs:

- Constituents of chairman and Ranking Member explain need for provision, ask for support.
- Constituents, champion's staff, advocates ask other committee members to convey support to chairman or Ranking Member.
- If there is a sign-on letter to chairman, constituents ask their Members to sign it.

A NOTE ABOUT STAFFERS



- At the federal level, most communication is with staffers, not the Members of Congress.
- Congressional staffers have a lot of discretion; make many preliminary decisions.
- In most cases, you must win over staffers before you win over their "bosses" (Members).
- Staffers of supporters can provide strategic guidance (e.g., which committee members to approach and what they care about).

2017-2018 – a challenging time!



- F2F funding to expire at end of FY 2017 (Sept. 30, 2017).
- House and Senate committee chairs were:
 - Rep. Greg Walden (R-OR) (Energy & Commerce)
 - Sen. Orrin Hatch (R-UT) (Finance)
- Ranking Democratic Members were:
 - Rep. Frank Pallone (D-NJ) longtime champion
 - Sen. Ron Wyden (D-OR) previous supporter



HOUSE

- April, Sept. 2017- FV staff met with Walden's staffer, new to issue, receptive to FV "ask" to expand program.
- Rep. Pallone asked that F2F expansion be included in chairman's mark.
- Oct. 2017- Walden included F2F provision in his mark for "health extenders;" approved by full committee.
- Nov. 2017- Full House passed bill that included F2F expansion.



SENATE

- Jurisdiction for F2F program in Finance Committee, chaired by Sen. Orrin Hatch (R-UT).
- Oct. 2017- Committee's draft "health extenders" bill included a 2-yr extension of F2F funding but not the expansion for territories and tribes or increased funding.
- Mission: Get Chairman Hatch to agree to the House F2F provision when the two chambers negotiated a final bill.



To influence Senator Hatch:

- FV staff and Utah FV affiliate (FV SAO) communicated with Chairman Hatch's staffer (new to issue).
- Utah affiliate sought partner organizations to give Hatch staffer information about Indian needs in Utah.



To influence Senator Hatch:

- Finance Committee Ranking Member Wyden (D-OR) and his staff communicated support Hatch staff.
- FV staff and constituents communicated with staff of the Senate Indian Affairs Committee; asked them to contact Hatch.



To influence Senator Hatch:

- All delegates from territories signed a letter to Hatch and Wyden asking for support of House provision.
- Letter reminded Hatch that Puerto Rico commission he chaired recommended that Congress consider expanding F2Fs to all territories. (Based on testimony from FV and Puerto Rico family leader.)



Back to Walden:

- FV decided to give an award to Walden for his support of F2F expansion.
- He accepted award in his "hide-away" from Oregon F2F staff in DC for FV conference.
- This was great chance to educate him personally and reinforce his support, likelihood of pushing for F2F in final bill.

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Nov. 2017 constituent Hill visits



During Family Voices Family Leadership conference in DC, House-Senate negotiations on final bill were underway. **Family Voices:**

- Urged conference attendees to make appointments with their Members.
- Provided instructions on how to make appointments, how to conduct Hill visits.
- Provided materials to leave with Hill staffers ("leave-behinds").

Nov. 2017 constituent Hill visits



F2Fs and SAOs:

- Visited their Members' offices about the need for the House F2F provision.
- Asked their Senators to contact Sen. Hatch about the need for the House F2F provision.
- Invited Members and staff to FV Hill reception.
- If possible, presented awards to selected Members in their offices.

OUTCOME – VICTORY!



After months on much bigger issues, the Bipartisan Budget Act of 2018:

- Extended F2F funding for two more years (FYs 2018 and 2019).
- Expanded the program to serve families in territories and tribes, adding 5 F2Fs for territories, at least one for tribes.
- Increased funding by \$1 million per year.

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But here we go again...



F2Fs need funding for FY 2020 and beyond.

- Funding expires at the end of this federal fiscal year (Sept. 30, 2019).
- The process begins again FV staff and constituents will communicate with Members and staffers, and seek support from partner organizations.
- In May, F2Fs and SAOs will be in DC and will do "Hill meetings."

SOME KEY LESSONS



Constituents & champions are key!

Constituents ("Grassroots")



Constituents have influence!

Parents, voting-age children, young adults, teachers, health care providers, educators, and other constituents are powerful – especially in an organized group!

Mobilize constituents



Leaders can:

- Identify family leaders and/or families in states of a committee member.
- Contact them (and contact them again) to ask them to contact the offices of their Members of Congress (via visit, phone, Facebook, Twitter).
- Provide instructions, talking points, reassurance.
- Provide materials for them to give Members/staffers (if applicable).

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Arrange meetings



Ideally, leaders arrange meetings between the Member and affected constituent families, in DC or locally.

Have them bring children, or at least photos/ short videos of their children.

A visit is worth a thousand words



Invite Members/staffers for a visit ---

... to relevant sites – hospitals, schools, constituents' homes.

... to workshops or meetings

... to speak at an event.

(Best chance to meet constituents; forces staff and maybe Member to learn about issue).

Tell constituent stories



- Collect and present stories and photos of constituents affected. (Little Lobbyists)
- Explain how your program helps the Member's constituents/district/state.
- Provide data on outcomes, cost savings.

Other actions leaders can take



- Identify "grasstops" who may be able to reach Member (e.g., state or local elected official, Member's friend, relative, etc.)
- Enlist partner organizations (local, state, national) to contact Members/staff and to mobilize their members.

CHAMPIONS ARE KEY



A champion is a Member of Congress who is willing to use their political capital and devote staff time to get legislation enacted.

How do you get a champion?

It's up to you!

Develop a relationship



Cultivate a relationship with Member and staffers:

- Offer yourself as a resource; tell the staff how you can help them learn about issues and/or help their constituents.
- Ask if the Member has a relevant advisory committee you can serve on.
- Send the appropriate DC and local legislative staffers your newsletter.
- Ask the Member or staffer to speak to your group or attend an event.
- Give the Member an award, if appropriate.
- Meet with the DC staffer whenever you are in DC; visit relevant local staffers.'
- Meet with the Member at home or in DC.

Choose a champion to cultivate



For a specific legislative goal --

Identify someone, preferably with whom you already have a relationship, who is:

- committed to the issue
- on the committee of jurisdiction
- in the majority party

Try to find another committee champion from the minority party.

Do your homework



- Figure out Members' (and staffers')
 interests, causes (e.g., interest in a specific
 disease, population, rural issues);
 educational and work history, and history on
 issues.
- Look at online bios, talk to your network, colleagues.

THANK SUPPORTERS!



Always celebrate successes!

Reward legislators AND STAFF who've supported your cause:

- Send notes of thanks from constituents.
- Send notes of thanks to congressional staff.
- Present awards, if appropriate. (You can reward someone for their position on your issue without agreeing with everything they do. No permanent friends, no permanent enemies!)

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Reward grassroots too!



Let constituents know that they made a difference.

Even if goal not achieved, there were gains -

- Building relationships and trust with Members and staffers.
- Educating Members and staffers about the issues.
- Getting practice in advocacy.

Resources



Public Policy & Advocacy at Family Voices: http://familyvoices.org/publicpolicy/

Policy Advocacy Webinars & Resources at National PLACE:

www.parentsatthetable.org/storage/app/media/resources/Main%20Resources/

Questions and Answers





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October 3, 2018



Washington DC Update



Resource eBlast September 2018

Sharing Resources for Families of Children with Special Healthcare Needs

WASHINGTON DC UPDATE 10/3/2018

This week, the big news (not related to the Supreme Court nomination) is the passage of a bipartisan agreement on opioid legislation, which was approved by the House on September 28 and is expected to be passed by the Senate this week. The proposed rule about whether an immigrant might become a "public-charge," which was explained in last week's Update, still has not been published in the Federal Register. This week's Update also includes resources about EPSDT and more.

NEW from CMS: Attention Assisters Who Are Helping Consumers

Impacted By Hurricane Florence

Special Enrollment Period Available for Victims of 2018 Hurricane Florence. On August 9,



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Access members-only resources including webinar series on public policy advocacy strategies & tools



Thank You!



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