

Family-to-Family Health Information Centers: Current Status and Policy Considerations

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Family-to-Family Health Information Centers (F2F HIC) receive mandatory appropriations to provide information, education, technical assistance, and peer support to families of [children and youth with special health care needs \(CYSHCN\)](#). Currently, the program [receives a mandatory appropriation through FY2024](#). F2F HIC aim to promote optimal health and well-being for CYSHCN and their families by advancing systems of care and ensuring that families and health professionals partner in all levels of shared decisionmaking. F2F HIC are nonprofit, family-led and family-staffed organizations in [all 50 states, six U.S. territories \(including the District of Columbia\), and three tribal communities](#). The program is administered by the [Maternal and Child Health Bureau \(MCHB\)](#) within the Health Resources and Services Administration (HRSA) of the Department of Health and Human Services (HHS). This Insight provides an overview of the current program, the national scope of CYSHCN, and the program's funding history. It also offers considerations for Congress regarding policy and funding options beyond FY2024.

Current Program

The [current program](#) supports 59 F2F HIC in delivering patient-centered information, education, technical assistance, and peer support. Additional legislatively required activities include

- assisting families of CYSHCN in making informed choices about health care in order to promote good treatment decisions, cost-effectiveness, and improved health outcomes;
- providing information regarding health needs of, and resources available to, CYSHCN;
- identifying successful health care models for CYSHCN;
- developing, with representatives of providers, managed care organizations, health care purchasers, and appropriate state agencies, a model for collaboration between families of CYSHCN and health professionals;
- providing training and guidance regarding the care of CYSHCN;
- conducting outreach activities for families, health professionals, schools, and other appropriate entities; and

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- staffing F2F HICs with families of CYSHCN who have expertise in federal and state health care systems, and with health professionals.

The program aims to [increase representation](#) from underrepresented and diverse communities based on recent evidence that special health care needs are more [common among non-Hispanic Black children](#) and children [living in a low-income household](#). Recently, [the program](#) also began implementing activities to address long-term impacts of COVID-19, primarily through education about telehealth and vaccination services.

Competitive grants awarded to individual grantees ranged between \$49,000 to \$96,750 in FY2023. Any domestic public or private entity is eligible to apply for funds up to [an estimated maximum](#). [Table 1](#) displays average funding per grantee from FY2014 to FY2023.

Table 1. F2F HIC Funding per Grantee, FY2014-FY2023

Fiscal Year	Average Grantee Amount	Difference From Prior Fiscal Year
FY2023	\$89,136	-\$1,381
FY2022	\$90,517	\$1,242
FY2021	\$89,275	\$164
FY2020	\$89,111	-\$7,647
FY2019	\$96,758	\$8
FY2018	\$96,750	\$7,107
FY2017	\$89,643	-\$3,530
FY2016	\$93,173	-\$1,143
FY2015	\$94,316	-\$1,384
FY2014	\$95,700	\$ 0

Source: CRS analysis of HRSA's Congressional Budget Justifications, FY2014-FY2024.

Note: HRSA's FY2024 Congressional Budget Justification is available on HRSA's [Budget page](#).

National Scope: Families and CYSHNs

According to the [2019-2020 National Survey of Children's Health \(NSCH\)](#), [over 14 million children](#) in the United States have a special health care need, with substantial [geographic variation](#). Further, more than one in four families (28.6%) had at least one CYSHCN. [Families of CYSHCNs](#) often experience chronic stress and are at risk for additional adverse health and social-emotional outcomes.

According to HRSA, F2F HIC provided services to over [204,000 families and 103,000 health professionals in FY2021](#). Grantee data indicate that service recipients report a high level of satisfaction with the information and services provided by F2F HIC.

Funding History

From FY2002 through FY2006, HHS funded F2F HIC in 36 states using a combination of [various program authorities and direct appropriations](#). The [Deficit Reduction Act of 2005](#) (DRA, P.L. 109-171) authorized mandatory appropriations under [Section 501](#) of Title V of the Social Security Act (P.L. 74-271). The DRA provided incremental funding from FY2007 through FY2009 (see [Table 2](#)) and required F2F HIC to be developed in all states by FY2009.

The program received a mandatory appropriation of \$5 million from FY2009 through FY2017. The program's geographic reach was expanded by the [Bipartisan Budget Act of 2018](#) (P.L. 115-123), which required that additional centers be developed in all territories and at least one tribal community. This law also increased annual appropriations to \$6 million from FY2018 through FY2019. The F2F HIC program was most recently extended [through FY2024](#) under the Sustaining Excellence in Medicaid Act of 2019 (P.L. 116-39).

Table 2. F2F HIC Legislation and Appropriation History

Law	Mandatory Appropriations (millions)	Changes
Deficit Reduction Act of 2005 (P.L. 109-171)	\$3 \$4 \$5	Authorized incremental funding increases for FY2007-FY2009; established statewide program under Title V of the Social Security Act
Patient Protection and Affordable Care Act (P.L. 111-148)	\$5	Authorized funding for FY2010-FY2012
American Taxpayer Relief Act of 2012 (P.L. 112-240)	\$5	Authorized funding for FY2013
Bipartisan Budget Act of 2013 (P.L. 113-67)	\$2.5	Authorized funding for FY2014 (half-year)
Protecting Access to Medicare Act of 2014 (P.L. 113-93)	\$2.5 \$2.5	Authorized half-year funding for both FY2014 and FY2015
Medicare Access and CHIP Reauthorization Act of 2015 (P.L. 114-10)	\$5	Authorized funding for FY2015-FY2017; struck partial funding for FY2015
Bipartisan Budget Act of 2018 (P.L. 115-123)	\$6	Authorized funding for FY2018-FY2019; required F2F HIC to be developed in all territories and at least one developed for tribal communities.
Sustaining Excellence in Medicaid Act of 2019 (P.L. 116-39)	\$6	Authorized funding for FY2020-FY2024

Source: CRS analysis of legislation on Congress.gov.

Policy Considerations

Legislation has not been introduced to extend funding for the F2F HIC program. Should Congress decide to extend funding, Congress may face multiple policy questions, including the following:

- Are statewide services sufficiently supported by current funding levels? Funding has remained relatively consistent since the program's enactment in 2005 (see **Table 2**).
- Does the \$1 million increase [from 2018](#) adequately support the program's expanded geographic reach and focus?
- Generally, each state/territory receives a similar funding level. Should the distribution of funds weigh other factors, such as the statewide prevalence of families with CYSHCN, or state population?
- CRS was unable to locate any relevant program evaluations; Congress may wish to consider whether the program has been sufficiently evaluated and whether a funding renewal should consider a program evaluation.

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