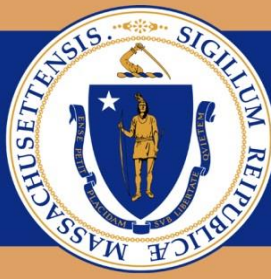


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Chapter 171 Report and Annual Individual and Family Support Plan

Fiscal Year 2023

November 2022



**Massachusetts Department of Public Health
Annual Family Support Plan
Fiscal Year 2023 (FY23)**

Overview

The mission of the Massachusetts Department of Public Health (DPH) is to promote the health and well-being of all residents of the Commonwealth by ensuring access to high-quality public health and healthcare services, and by focusing on prevention, wellness, and health equity for all people.

DPH programs, services, and educational initiatives are designed to address social determinants of health, defined as “the conditions in which people are born, grow, live, work, and age, which contribute to health inequities,” and to recognize and strive to eliminate health disparities among populations in Massachusetts wherever they may exist. DPH works to prevent disease and disability and reduce the impact on individuals and society of preventable health conditions and secondary effects.

Within DPH, the Bureau of Family Health and Nutrition (BFHN) is home to many programs serving children and youth and their families, including the Massachusetts Maternal & Child Health (MCH) Title V Program. Title V is an 87-year-old program enacted as part of the Social Security Act of 1935. Title V works to ensure the health of the nation’s mothers, women, children, and families. This includes children and youth with disabilities, special health needs and chronic illness and their families who are served by the Early Intervention Division (EI) and the Division for Children & Youth with Special Health Needs (DCYSHN). The BFHN Office of Family Initiatives (OFI) in collaboration with DCYSHN takes the lead responsibility for developing the DPH Family Support Plan as mandated by *Chapter 171 of the Acts of 2002: An Act Providing Support to Individuals with Disabilities and Their Families*. To ensure meaningful family involvement and input, BFHN examines existing programs annually. One way this is done is by soliciting family/consumer input, which is used to increase the degree to which programs and services can be responsive and family-directed and provide more flexible supports. This ongoing work is entirely consistent with the Title V philosophy of meaningful and sustained family engagement in all aspects of policy development and program planning.

I. Family Support

DPH has a long-standing commitment to effective, collaborative partnerships with families and works to ensure that programming is responsive to needs identified by families and consumers. To ensure that this commitment is realized, DPH employs a broad definition and multi-faceted approach to family support, starting from a commitment to family-centered care, a core component of maternal and child health, which is defined by the federal Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) as:

"Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services."

As part of ongoing commitment to family engagement and racial equity across BFHN and throughout DPH, bureaus, divisions, and individual programs are working towards more inclusive, equitable programming that engages all families. Work to articulate these core values resulted in the commitment statements of Racial Equity and Family Engagement.

Commitment to Racial Equity

The impact of structural racism — the public policies, institutional practices, and social norms that together maintain racial hierarchies — is often overlooked or unacknowledged, yet it is pervasive and unmistakably harmful to everyone. The social marginalization and inequities that structural racism cultivates in housing, education, employment, the built and social environments, and health care are felt across generations, most acutely in communities of color. The Bureau of Family Health and Nutrition recognizes that systems of oppression need to be acknowledged and repaired by entities that helped create them. The Bureau is committed to improving the quality of life for all Commonwealth residents while eliminating the marginalization and inequities that threaten the lives of communities of color who are disproportionately affected by conditions leading to poor health outcomes.

Commitment to Family Engagement - Why Statement

The Bureau of Family Health & Nutrition (BFHN) believes that equitable and intentional partnerships with families and professionals lead to effective policies, programs, and practices.

*The Bureau's commitment to **family engagement** and **racial equity** are core values that inform our work. We understand that the family experience is vital in developing and implementing successful programs. The BFHN appreciates the richness that involving all stakeholders brings, and that strong partnerships help to ensure effective systems of care. We are committed to engaging with mothers, fathers, children, youth, families of all compositions and community members in a process of shared decision making where each voice carries equal weight.*

*We also recognize that this value has not always been accepted or promoted in society or in healthcare broadly. Historically, family voices - especially those with disabilities or from diverse cultures - were not included in healthcare decisions. Many believed that questioning healthcare providers was unacceptable because they knew best; healthcare was done to families. Advocacy, regulations, and mandates have advanced the standard of healthcare provision to be done with families. BFHN believes that **all** families - including Black, Indigenous, People of Color (BIPOC), White, and those with disabilities contribute expertise in healthcare decisions that affect themselves and others.*

In addition, DPH provides a variety of flexible family-identified supports, including a small amount of

discretionary funding to individual families to be used as needed for services and equipment not covered by insurance. DPH provides skill-building opportunities that assist families to become confident, well informed, active partners in their own children's health, and in policy development and systems enhancement. DPH programs provide information and referral to resources to assist families in the care of their children with special health needs and offer opportunities for family-to-family support and networking, recreational activities, and assistance with accessing community resources.

At DPH, many family support activities are housed within BFHN's Early Intervention Division (EI) and Division for Children & Youth with Special Health Needs (DCYSHN) and are overseen by the Director of the Office of Family Initiatives (OFI), which is a management position within BFHN. The Director's responsibilities include:

- Ensuring that all staff are aware of, receive information about, and know how to work in partnership with families,
- Ensuring that all Bureau initiatives include families/consumers in planning and monitoring activities,
- Developing new and ongoing opportunities for family involvement,
- Providing training, mentoring, financial and other supports to families partnering in planning, policy making, and program implementation,
- Identifying and sharing emerging issues for CYSHN and their families,
- Representing BFHN and its commitment to family-centered services in interagency initiatives, and with other organizations on the state and national level,
- Providing the "family voice," both personally and via inclusion of other family members and family organizations, in Bureau and Department activities, and;
- Utilizing a racial equity lens across all of the above responsibilities

In FY20, both divisions worked to expand engagement and partnerships with families and to ensure that all staff understand and implement the definitions and commitment. These responsibilities are also included in staff performance evaluations. Staff works to identify activities for families such as offering skill building to successfully navigate systems of care and creation of opportunities to serve in advisory functions are some examples. DPH continues to be a member of a cross-sector initiative of 11 state agencies and a coalition of more than 500 community stakeholders that developed and disseminated the [Prenatal through Young Adulthood Family Engagement Framework](#), a roadmap for family engagement for the state, and is working to implement the Framework's principles and strategies. This framework serves as a template for the Department and defines family engagement as one of its critical core values that guides ongoing work:

Family Engagement is the intentional practice of partnering with families to support positive outcomes in their lives and to improve and enhance our work by actively developing ways for families to share their lived experience and expertise.

Family Engagement is based on the belief in the importance of family involvement and leadership at the individual, community and systems level and is infused within the EI and DCYSHN core values as well as across BFHN.

Process for obtaining "substantial consultation" from families regarding flexible support needs

Since the start of the COVID-19 Pandemic Bureau staff have continuously heard from stake holders and families that the mental health of CYSHN and their families was a grave concern. At the same time, DPH fielded the COVID Community Impact Survey (CCIS) to broadly assess the impact of the pandemic on many areas of functioning for the citizens of the Commonwealth. Bureau staff participated in the development, promotion, and dissemination of the COVID Community Impact Survey and ongoing analysis of the data

received. The DCYSHN worked with the CCIS team to include questions to identify “special health care needs” in children and youth using the MCHB definition.¹ The EI and DCYSHN engaged with families utilizing their services and with community organizations serving this population to encourage a robust response across disability, race and ethnicity, language, and culture. A total of 786 caregivers of children & youth with special health needs - 80% white, 17% people of color (POC); 16% speaking a primary language other than English and 10% of whom identified as having a disability themselves gave input into the CCIS. Of these caregivers, more than half reported persistent poor mental health and episodes of post-traumatic stress disorder (PTSD) greater than the general population for themselves and/or their children. Caregivers were broadly more worried about basic needs such as food security, housing, job loss, and access to mental health supports than the general population.²

This statewide survey provides an important resource for understanding the needs of CYSHN and their families in Massachusetts and far exceeds data gleaned from the National Survey of Children’s Health.

A second strong response around mental health issues was received from youth and young adults with special health needs (YYASHN) including (641 or 21% of youth respondents) identified as having cognitive, mobility, vision, and other special health needs; 46% were under 18 and 54% over the age of 18, while 32% identified a language other than English as their primary language. Among respondents, 75% of these youth reported “feeling sad or hopeless every day for 2+ weeks and reported needing access to mental health services.”³

Based on the clearly articulated needs demonstrated by the data from the CCIS regarding gaps, inequities, and access issues, BFHN has decided to make addressing the significant mental health differences experienced by these two groups as compared to peers, the focus of its FY23 Chapter 171 Family Support Plan.⁴

This focus aligns with the Title V 2020-2025 priority to: Strengthen the capacity of the health system to promote mental health and emotional well-being; as well as the priority of the Massachusetts Early Intervention system to increase the number of infants and toddlers enrolled in Early Intervention who demonstrate improved positive social-emotional skills.

Focus Areas

In FY23, DPH will focus Chapter 171 activities in three primary areas:

1. Support the legislatively established MDPH PANDAS/PANS Advisory Council charged with advising on research, diagnosis, treatment, and education related to Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections and Pediatric Acute Neuropsychiatric Syndrome (PANDAS/PANS). Based on the devastating nature of these conditions to children and their families, as well as the cost to families, school systems, medical providers, and insurers, the DCYSHN will actively engage families about what is needed to support their mental health needs. DCYSHN will partner with two parent-led community organizations to train DCYSHN staff about mental health and trauma-informed/healing-centered care for this population.

¹ The Maternal and Child Health Bureau defines CYSHCN as children who “have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”.

² <https://www.mass.gov/resource/covid-19-community-impact-survey>

³ <https://www.mass.gov/info-details/ccis-spotlight-youth>

⁴ [https://urldefense.com/v3/https://www.bostonglobe.com/2022/06/07/metro/numbers-just-continue-rise-patients-awaiting-psychiatric-treatment-crowd-emergency-rooms/;!!CUhgQOZqV7M!y-WSn-aLLfd4qQ8UucPt63QTY_L1_DyPEskDXhXZCGQZX3o3N5NWGdxQTfmrJ7GyBfhcS7DI\\$](https://urldefense.com/v3/https://www.bostonglobe.com/2022/06/07/metro/numbers-just-continue-rise-patients-awaiting-psychiatric-treatment-crowd-emergency-rooms/;!!CUhgQOZqV7M!y-WSn-aLLfd4qQ8UucPt63QTY_L1_DyPEskDXhXZCGQZX3o3N5NWGdxQTfmrJ7GyBfhcS7DI$)

2. Convene sister agencies including DMH and Medicaid as well as DPH programs serving YYASHN and their families to share data as well as identify and disseminate strategies to expand mental and behavioral health access.
3. Learn about and make families aware of new resources as they become available for example the new Maternal & Child Health Mental Health Hot Line among others.
 - <https://mhffcnetwork.org/centers/global-mhffc/news/hrsa-launch-national-maternal-mental-health-hotline>

II. Family Empowerment and Family Leadership

Current and Ongoing Activities:

At DPH, family empowerment and family leadership activities are integrated and are offered in the following ways:

- Participation in policy development, program planning, implementation, and evaluation coupled with skill-building opportunities that assist families and consumers to confidently and effectively participate.
- Participation in the MCH Block Grant process, from needs assessment to priority setting, to implementation and evaluation.
- Participation on the federally mandated Interagency Coordinating Council (ICC) which assists and advises the Part C Early Intervention Program.
- Family TIES (Together in Enhancing Support), a program of the Federation for Children with Special Needs funded by DPH, is the statewide information and referral network for families of CYSHN and their providers. Family TIES staff are all parents of children with special health needs. Prior to the COVID-19 pandemic, staff were located in each of the DPH satellite offices, to build connections and familiarity with local resources. Staff continued to support families who called the toll-free line, their office numbers and emailed throughout FY22. Family TIES also serves as the Massachusetts Parent-to-Parent program, an affiliate of P2P USA, connecting families with similar life circumstances, and as the Early Intervention Central Directory. Families who access services from Family TIES are offered opportunities to become advisors to DPH and to take on roles within DPH programs and other public policy venues. Training, mentoring, and financial compensation is available to these families.
- The Early Intervention Parent Leadership Project (EIPLP), which is a parent-designed and staffed project that reaches families whose children are enrolled in EI, offering skill-building for leadership and lifelong advocacy skills development. Through the EIPLP, DPH offers a variety of opportunities that assist families to take on roles across the early childhood and special health needs systems of care. Begun in FY20 and continuing, OFI and the EIPLP provided *Finding Your Footing: Using Your Family's Experience to Improve Systems*; a series of virtual skill-building sessions to develop leadership and advocacy skills including effective communication, dispute resolution and serving on teams. To date, 22 parents have participated, and have used the skills learned to review RFRs, present at conferences and support other families. In the first cohort of 14, 8 attended training to learn how to participate in RFR review and took part in a review of a procurement for Early Intervention Specialty Services. 8 families from cohorts 1 & 2 attended the annual Visions of Community and Massachusetts Early Intervention Consortium Conference. Three families used their new skills to take part in Interagency Coordinating Council activities,
- Parents are encouraged and supported to partner with their local EI programs, at regional early childhood events, on the state level as advisors to the DPH, as members of the federally mandated Interagency Coordinating Council (ICC), and nationally to share information about Massachusetts and to learn and bring home information from other states about ways that families can help define and improve services systems. Over the past several years, EIPLP has identified and supported six new members for the ICC from culturally, racially, and linguistically diverse groups to participate in EI and DCYSHN activities and has taken a leadership role in working across the early childhood and special health needs system of care to support racial equity work.
- The DCYSHN Director, Assistant Director, Community Support Line (CSL) Program Manager and Complex Care Needs Director participate in the Massachusetts Respite Coalition to raise awareness of the needs of children and youth with special health care needs and their families.
- Families are surveyed at a minimum of annually and often more frequently as part of phone contacts about support and training needs and best uses of flexible funds through the Office of Family Initiatives, Community Support Line, Care Coordination, and Regional Consultation Programs. These programs also

provide training and skill-building opportunities for families to grow their knowledge of systems of care and their leadership and advocacy skills.

- The Early Intervention Division provided individualized training and technical assistance to a parent so that she could serve as the ICC co-chair. Training and support included developing agendas and facilitating meetings.
- The Early Intervention Division presented data on its outcomes related to family perceptions of EI services and engaged ICC parent members in robust discussions about how and why response rates differ by a family's race/ethnicity. Information from this presentation was part of the decision to add an additional question about the impact of race/ethnicity/language to the FY23 NCSEAM Family Survey.
- The Early Intervention Division presented data on its outcomes related to toddlers' progress and engaged ICC parent members in discussions to help establish targets for future fiscal years.

New Initiatives:

- OFI will offer a third *Finding Your Footing* training series beginning September 2022 with a goal of engaging 15 families.
- DCYSHN will develop, support, and sustain Family Advisory Councils for the Pediatric Palliative Care Network and the Catastrophic Illness in Children Relief Fund and a Youth and Young Adult with Special Health Needs (YYASHN) Advisory Council for the DCYSHN.
- EI and DCYSHN leadership will promote increased opportunities for training and skill building around racial justice, inequities, and health disparities within DPH and in collaboration with other state agencies. These opportunities will be made available to division staff as well as external partners
- The OFI Director, other Bureau staff and members of the MCH Title V Block Grant Implementation Team for Family, Father & Youth Engagement will build on the coalition established through the Family Engagement Framework to increase participation of families and providers from diverse communities for the purpose of learning more about the specific challenges and support needs based on culture, race, ethnicity and language.
- The DCYSHN Director will continue and enhance collaboration with the DPH Offices of Preparedness and Emergency Management and Health Equity to ensure that the specific needs of CYSHN and their families are included in all planning.
- OFI will identify, recruit, host, and summarize focus groups for families during the early part of FY23 to prepare for a procurement of new early intervention services providers in FY24.

III. Family Support Resources and Funding

Current and Ongoing Activities:

Family support activities continue to focus on skill building, leadership development, and increasing knowledge of and expansion of family engagement opportunities at the community level; production and dissemination of informational materials, assistance in forming local support groups, supporting Early Intervention and community programs to address racial equity and health disparities and expansion of the statewide Parent-to-Parent program. The Parent-to-Parent program trains volunteer parents to offer telephone support to families with similar life experiences. In FY22, 43 of 117 requested Parent-to-Parent matches were completed. Of the 117, 35 requests needed information and referral and were closed after connection to Family TIES regional coordinators were made. The remaining 39 requests will be carried over into FY23. “*Listen and Learn*,” the training program for mentor parents, is available in Chinese, Vietnamese, Haitian Creole, Portuguese, and Spanish was offered 3 times. Currently, there are 224 active trained support parents with the capacity to offer support in 23 languages. The Parent-to-Parent coordinator debriefs each mentor parent at the conclusion of a match to identify any challenges or trends. Materials developed in response to previous substantial consultation from previous Chapter 171 Plans, including a brochure called *A Bridge to Adult Health Coverage and Financial Benefits*, medical home fact sheets for families available in six languages, and a *Guide to Using Health Information on the Internet* continue to be distributed. DCYSHN maintains a website to support families, youth and providers around health transition: www.mass.gov/dph/youthtransition. The website contains checklists, tip sheets, training curricula, and links to external useful transition resources.

BFHN maintains a toll-free Community Support Line (CSL) available to families of CYSHN and their providers. In FY22, the CSL received 676 calls of which 188 were from families. Social workers on the CSL offer information about statewide resources, public benefits, and other DCYSHN and Bureau programs and make referrals to Care Coordination for eligible families. When families need information and support from other agencies, staff helps them identify which agency would have primary responsibility for their presenting issue and facilitates connections with these agencies.

An additional toll-free line staffed by Family TIES Parent Coordinators provides information about local and community resources and responded to more than 2500 unduplicated calls from families and providers in FY22.

The Early Intervention Parent Leadership Project hosts robust social media sites where information about resources for families are posted. The Project has 1219 Facebook likes and an estimated reach of 12,953 looks at content. An Instagram account has 144 followers and an estimated 227 unique accounts that saw their posts. 203 followers on Twitter have access to resources for families.

Additional BFHN Family Support Programs

Down Syndrome

In accordance with Chapter 126 of the Acts of 2012, which named DPH to provide families receiving a pre or post-natal diagnosis of Down syndrome, "up-to-date evidence-based, information for providers and families," DCYSHN continues to work in collaboration the Massachusetts Down Syndrome Congress to share information, monitor and update the website of resources at www.mass.gov/dph/downsyndrome.

Early Intervention

Family support initiatives are provided by six statewide Early Intervention Regional Consultation Programs (RCPs). Each RCP receives funding to provide respite services to the families they serve. RCP staff provides training and on-site consultation to center-based and family childcare programs and, ranging from birth to age three with complex medical needs. EIPLP and Family TIES collaborates with the RCPs to provide socialization and networking opportunities for families whose children have complex medical needs. In

FY22, the Early Intervention Division hired a full-time employee to oversee this work and ensure appropriate cross-collaboration with DCYSHN and other specialty services.

MASSTART

Massachusetts Technology Assistance Resource Team (MASSTART) supports children with complex medical conditions by consulting to schools and families on developing a safe plan of care while attending school. Children with complex health conditions often require medical treatment, medication or observation that requires skilled nursing intervention while at school. MASSTART providers assist in developing children's individualized health care plans and emergency plans, train school staff to understand and meet children's special needs, conduct educational and training programs, and provide information and referrals to community-based services. By ensuring safety in school for children with complex needs, it supports the educational goal of placement in the least restrictive setting. In FY21, DPH contracted with two hospitals to provide this service. In FY21, MASSTART served 259 children and youth under age 22. MASSTART received 114 new referrals and responded to 267 technical assistance requests. MASSTART also held regular trainings for school nurses and school staff. MASSTART providers collaborated regularly within their regions by attending multi-agency collaboration meetings and worked closely with DPH School Health Unit and Regional School Health Advisors. Families faced unprecedented challenges due to the pandemic as they dealt with school closures, the provision of remote school services, and transition back to in-person school services. MASSTART provided consultation, outreach, and training via virtual platforms and to serve families without interruption.

MassCARE

MassCARE (Massachusetts Community AIDS Resource Enhancement) is a statewide program that provides access to coordinated, comprehensive, family-centered, culturally and linguistically competent medical care, social service support and peer services for women, infants, children and youth living with HIV and their family members. MassCARE's transition guidebook *Moving on Positively* has been available as a resource on the Target HIV website (the national Ryan White Program's resource center) for several years. In FY21, five HIV-positive youth/young adults received transition planning services and updated their transition plan. In FY21, MassCARE piloted a Mentorship Initiative with one youth from each site to support transition-related needs. The Initiative was updated based on feedback from youth and community sites during the pilot; it will be a standing service going forward.

Universal Newborn Hearing Screening Program

In FY22, the Universal Newborn Hearing Screening Program (UNHSP) made 3,359 calls and sent 836 letters to families whose children either did not pass or missed their initial hearing screening or diagnostic center appointments. Of 150 infants diagnosed with hearing loss, 125 were enrolled in Early Intervention.

A Memorandum of Understanding allows DPH to connect families to the Mass Commission for the Deaf and Hard of Hearing (MCDHH) which provides additional supports. The UNHSP employs a parent of a child with hearing loss as a parent consultant. This consultant makes personal contact with every family whose child receives a diagnosis of hearing loss to offer family-to-family support and information about community and statewide resources. In FY22, the program distributed 48,823 brochures in 13 languages, as well as 147 English and Spanish parent information kits, to families and providers.

The UNHSP has a strong focus on family support activities. In FY22, the program hosted four social events attended by 176 parents of children with hearing loss.

Pediatric Palliative Care Network

The Pediatric Palliative Care Network (PPCN) provides services to children and youth with life-limiting conditions and their families through contracts with eight pediatric hospice organizations. In FY22, 691 clients received palliative care services including pain and symptom management, case management, respite, complementary therapies, and bereavement care.

Flexible Funding

In addition to these programs and services, DPH sets aside flexible funding available to families to address medical and other health-related needs not covered by other sources. Special funds help eligible families purchase essential supports, such as hearing aids, medications, assistive technology, respite services, home and vehicle modification, and reimbursement for travel expenses incurred for the care of their children with special health needs. Funds are disseminated through DPH vendors and in some cases from DPH directly to families. Below are examples of funding available to families through BFHN programs in FY22:

- 160 children and families received \$2,010,629 million in funding from the Catastrophic Illness in Children Relief Fund (CICRF).
- Six **RCPs** distributed \$274,197 to 572 families with infants and toddlers enrolled in the EI system for respite services as determined by eligible families.
- The Care Coordination program distributed \$185,217 of family support funds to 507 families. Clients of the program who received this income-based funding can use the funds for respite, recreational activities for their children, equipment such as air conditioners, etc.
- \$20,000 was available through the Hearing Aid Program for Children. Fourteen children received assistance with purchase of hearing aids.
- \$88,000 was allocated to OFI for family involvement activities across BFHN, including participation in focus groups, proposal reviews, as trainers, community-based projects, attendance at conferences and other skill building opportunities, at social activities and as participants in leadership training. About 250 Family Advisors, individuals who offer to assist EI and DCYSHN, responded to those and other requests for their expertise. 15 Advisors were connected to opportunities all of which provided stipends for their input.

New Initiatives:

In FY23, BFHN divisions including EI, CYSHN, and OFI will:

- Expand outreach to diverse communities to find under-resourced families to learn about and access Early Intervention services if eligible as well as other DPH resources and supports.
- Complete an evaluation of OFI projects and activities to provide insights in increasing family self-efficacy and identify existing and needed data and measures that will support spread and sustainability.
- Work to identify new funding sources for increased family support, leadership development and engagement.
- Work across the Bureau to identify more opportunities for Family Advisors to share their expertise
- Continue to expand Parent-to-Parent support to families of children who are deaf or hard of hearing before six months of age through collaboration between the Universal Newborn Hearing Screening and Family TIES programs.
- Expand collaboration with MassHealth and other state agencies to increase access to mental and behavioral health supports for CYSHN.
- Launch a Youth & Young Adult with Special Health Needs (YYASHN) Transition Advisory Group.
- Complete and disseminate a Health Transition Toolkit specifically for YYASHN and their families that will include a section on mental health.
- Provide education to the DCYSHN team about trauma-informed and healing centered care to develop an internal culture of support, trust and understanding that can strengthen the team in providing similar care and sensitivity to the needs of families of CYSHN.

- Expand training and technical assistance provided to early intervention services programs including in person or virtual visits to all EI programs, a menu of skill building opportunities for families enrolled in EI and follow-up calls to families who call Family TIES for information about EI.

IV. Accessing Services and Supports

Current and Ongoing Activities:

DPH uses a variety of strategies to inform families and consumers about availability of and access to services. Some of these include public service announcements, infographics, websites, Early Intervention Child Find, dissemination of Medical Home fact sheets for families and providers, program specific newsletters such as EIPLP's *Parent Perspective*, and the MassCARE newsletter. All staff present regularly at conferences and to community groups. Several programs have active Facebook pages that post articles, ideas, and links to local, statewide, and national sites with interesting and helpful resources for families whose children have special health needs: DCYSHN (1,936 likes), UNHSP (900 likes), and EIPLP (1,216 likes). The Community Support Line, CICRF, Family TIES, Care Coordination, and PPCN staff routinely conduct outreach to hospitals, schools, and community settings where individuals with disabilities and their families receive services to share information.

These programs work together regionally to ensure that family needs are met. The DPH Public Benefits and Health Policy Specialist provides training to families and providers across the state and offers technical assistance by telephone and online and at in-person trainings. In FY22, 172 parents attended presentations about public benefits. During this time, 37 parents received personalized TA and training from the Public Benefits and Health Policy Specialist. Community Support Line, Family TIES and EIPLP all maintain toll-free numbers. Family TIES and EIPLP also host websites and listservs. Family TIES distributed 101 project brochures in English, Spanish and Portuguese and 1,000 Resource Directories. Seven editions (one hardcopy and six electronic) of the *Parent Perspective* newsletter have been distributed to 25,000+ families and professionals.

These materials are available for download on project websites. DCYSHN program information is available at <https://www.mass.gov/orgs/division-for-children-youth-with-special-health-needs>. Previous Family Support Plans, are available online at: <https://archives.lib.state.ma.us/handle/2452/396574ds>. Information about the Early Intervention Division is available at: <https://www.mass.gov/orgs/early-intervention-division>

DCYSHN program brochures which have contact information are widely disseminated and available in English, Portuguese, and Spanish. There is interactive capability on the DPH website and on BFHN project sites for families to offer feedback and suggestions.

New Initiatives:

- EI will adapt the NCSEAM (National Center for Special Education Accountability & Monitoring) Family Survey which measures Family Outcomes as a result of participation in Early Intervention to gather information about family perception of the impact of color, race, ethnicity and language on EI services.
- In collaboration with IT, DCYSHN will develop and launch a universal database to integrate information across its programs and capture a more complete picture of families served and the needs they bring.
- OFI programs will continue and expand information gathering and dissemination on social media and other virtual mechanisms.
- Continue to make DCYSHN and EI websites more accessible to individuals with disabilities and families of children and youth with special health needs and their providers.

EIPLP will add interactive capability to the project website.

V. Culturally Competent Outreach & Support

Current and Ongoing Initiatives:

Collaboration with the Office of Health Equity (OHE) is ongoing within DCYSHN. OHE provides resources and technical advice on the application of the national CLAS (Culturally & Linguistically Appropriate Services) standards to ensure that programs are able to integrate and use the standards effectively (<http://www.mass.gov/eohhs/docs/dph/health-equity/clas-intro.pdf>). OHE also provides guidance and support on principles, policies, and tools for language access and disability issues, including access to the Health and Disability Partnership, DPH's statewide advisory board on disability issues.

Materials about all programs for individuals with special health needs and their families are available in a variety of languages, including Spanish, Portuguese, Haitian Creole, Russian, Cambodian, and Vietnamese. All programs have staff with multiple language capability and have access to interpreters, including American Sign Language (ASL) and tactile interpreters for Deaf/Hard of Hearing and visually impaired individuals. Whenever possible, DPH hires or contracts with individuals who are bilingual, bicultural, and familiar with the culture and customs of families who receive services from our programs.⁵

Outreach initiatives, designed to build relationships and reduce health disparities, take place with community-based organizations where racially, ethnically, linguistically, and culturally diverse individuals and families receive services and are comfortable. These include community health centers, WIC offices, faith institutions and family organizations. Family TIES contracts with native Spanish and Portuguese speakers to respond to requests for information and referral and Parent-to-Parent matches. As part of a major focus on outreach to underserved groups, Family TIES staff works with a number of community-based organizations, including, but not limited to, the Somali Development Centers in Holyoke and Boston, SCAN 360 serving the Hispanic population in Springfield, the Vietnamese Community Centers in Boston and Worcester, MAPS serving Portuguese speaking families, and the Haitian Community Center in Boston. This is an opportunity to share information about community resources and the availability of flexible family supports. As much as possible working remotely, In FY22, Family TIES staff continued targeted outreach to under-served populations to offer information about Early Intervention, DCYSHN programs, the Medical Home approach to care, managing the many services, appointments, specialists and paperwork involved in caring for medically complex children and transition from pediatric to adult health care.

As a priority in the MCH Block Grant process, DPH made a commitment to racial justice and health equity. Over the past three years, multiple training opportunities have been made available within BFHN and BCHAP (Bureau of Community Health and Prevention) first to leadership and then to staff more broadly to support them to understand the foundations of racial inequities and to strategize about how to apply this knowledge to our work. BFHN has developed and implemented racial equity workgroups in the areas of procurement, hiring, professional development and communications. In FY22, BFHN and DPH continued to make multiple opportunities including brown bag lunches, town hall meetings, and affinity groups available to all staff. DPH has developed and implemented a hiring protocol aimed at increasing the number of people of color, veterans, and those with disabilities in the work force.

The National Center for Special Education Accountability & Monitoring (NCSEAM) Family Survey is available in Haitian Creole, Portuguese, Vietnamese, English, and Spanish. In FY22, 2,804 surveys were completed and returned for a response rate of 46.16%. The Early Intervention Division continued to make the Family Survey available in Arabic, Chinese, English, Spanish, Portuguese, Vietnamese, and Haitian Creole through a web-based application.

OFI supported 22 parents to attend the virtual FY22 MEIC (Massachusetts Early Intervention Consortium) Conference. Care Coordination and EIPLP supported over 100 parents to attend the annual Federation for Children with Special Needs Visions of Community Conference.

⁵ <https://www.mass.gov/info-details/state-employee-diversity-dashboard>

Specific training about organizing complex and multiple records, emergency preparedness, and building community, and Parent-to-Parent support are available in Spanish, Portuguese, Chinese, and Vietnamese. 170 parents attended 23 training opportunities and six new mentor parents were trained in the Parent to Parent Listen & Learn curriculum. Turning 3-Transition from EI training is available in Spanish. In FY22, 231 people attended the English and Spanish trainings. The EIPLP newsletter parent articles and updates on the EI Family Survey are translated into Spanish in each edition. DCYSHN programs continued to utilize telephonic language lines provided by the Department to ensure effective communication with non-English speakers.

New Initiatives:

- The Early Intervention Division will require its contracted providers to complete the Culturally and Linguistically Appropriate Services Provider Self-Assessment and develop a workplan. EI has developed training for providers to orient them to the survey, the importance of the provision of CLAS, and how it relates to the family experience.
- The Catastrophic Illness in Children Relief Fund will expand an outreach initiative to Haitian families to ensure this population is aware of the supports available to them in caring for their CYSHN.
- The EI Family Survey information and other relevant resources sent to families through the Parent Perspective Newsletter will be translated into the six most widely spoken languages in the EI service population.
- OFI will expand collaboration with the Federation for Children with Special Needs Outreach Coordinators to share health information and resources with the culturally and linguistically diverse families they support.
- OFI will expand the welcome message on the Family TIES toll free line into six languages and create voice mail boxes in these languages to encourage families who speak languages other than English to use the program.
- OFI staff will expand outreach to faith-based organizations serving families from diverse cultures.

VI. Interagency Collaboration

Current and Ongoing Activities:

- Participation in ongoing work with 11 state agency partners, community stakeholders and the Statewide Family Engagement Center (SFEC) at the Federation for Children with Special Needs for implementation of the Family Engagement Framework; [Prenatal through Young Adulthood Family Engagement Framework](#). The OFI Director serves on the Family Engagement State Planning team along with the Division for Pregnancy, Infancy & Early Childhood's Early Childhood Systems Coordinator for Family Engagement & Training. Several other DPH staff are members of the state stakeholder group. The Planning Team, comprised of representatives from Department of Elementary & Secondary Education and Department of Early Education & Care, reviews information from stakeholder meetings. In FY22, this coalition hosted another 6 sessions for community stakeholders to share information and materials and to hear about their concerns, needs and progress in moving family engagement forward. With support from the Department of Elementary and Secondary Education (DESE), aspects of the Framework were turned into one-page flyers in simple language for use by families. These flyers were translated into Spanish, Portuguese and Mandarin and widely distributed at the community level.
- Ongoing work on State Systemic Improvement Plan (SSIP) for EI services with a focus on improving social and emotional well-being of children served in EI with input from the Interagency Coordinating Council, a federally mandated group that assists and advises DPH. Representation from DCF, DESE, DEEC, Mass Chapter of the American Academy of Pediatrics and parents.
- *EI collaborations include:*
 - Collaboration with Office of Refugee and Immigrant Health to develop training materials for Resettlement Agencies for Afghan and Haitian Families being resettled in the Commonwealth.
 - Collaboration with Early Education and Care to ensure families' access to EI services were uninterrupted during the increased COVID-19 cases due to the Omicron variant.
 - Collaboration with The Division of Pregnancy, Infancy, and Early Childhood to disseminate information about the Child Tax Credit to families enrolled in EI services.
 - Collaboration with The Nutrition Division to disseminate information about the formula recall to families enrolled in EI services.
 - Collaboration with Injury Prevention and Poison Control to disseminate information about its 12-part Injury Prevention Training for EI service providers working directly with families.
 - Collaboration with Injury Prevention and Poison Control to disseminate information about safe sleep practices for infants to EI service providers and directly to families.
 - Support for the Insurance Resource Center for Autism and Behavioral Health at the UMass Chan Medical School's Shriver Center.
- *Other collaborations include:*
 - Development of a cross agency data system to capture needs, services and outcomes for children birth to age 5 as part of the Preschool Development Grant Led by EHS.
 - Participation of EI and DCYSHN in the DPH Vaccine Equity Initiative (VEI) to reach families in 20 under resourced communities.
 - DCYSHN and EI participates on the State Special Education Advisory Board to share information about children with special health needs in public schools. In FY22, participation continued to be remote. DPH representatives have shared COVID-19 related information and resources with colleagues from other state agencies and with families.

- Continued collaboration with the Office of Refugee and Immigrant Health to support children and youth with special health needs from culturally and linguistically underserved populations.
- EI collaborates with the Interagency Coordinating Council (ICC), a federally mandated council that advises and assists the DPH as lead agency for the early intervention system in performing its duties, particularly in identifying sources of fiscal and other supports for early intervention services, ensuring appropriate transition services for eligible toddlers exiting early intervention, and preparing and submitting its annual report. The ICC's appointed members include parent representatives (i.e., parents of children aged 12 or younger who receive or have received EI) provider representatives (i.e., providers of early intervention services), and representatives from various state agencies (e.g., MassHealth, DESE, EEC).
- EI provides training and resources through the ICC to support racial equity and health disparities amelioration across the Early Childhood service system.
- UNHS collaboration with MCDHH to make early connections for families with children diagnosed with hearing loss.
- Participation in the Massachusetts Children's Vision Health Advisory Committee.
- DCYSHN meets regularly with the Coordinated Case Management Program at MassHealth.
- BFHN leadership and the Division of Pregnancy, Infancy & Early Childhood (PIE) participates on Young Children's Council, a public/private council that on social connectedness.
- PIE participates in Essentials for Childhood, a public-private partnership with the Children's Trust Fund, EEC, Department of Children and Families, Centers for Disease Control and Prevention (CDC), and business that promotes social-emotional well-being and creating safe, stable and nurturing environments for young children.
- Participation in a WIC Developmental Monitoring Program funded by CDC.
- BFHN staff participation on the Steering Committee of the Statewide Family Engagement Grant at the Federation for Children with Special Needs.

New Initiatives:

- Provide education to the DCYSHN team about trauma and trauma-informed and healing centered systems and learn how to apply to staff and the work done with children and families
- BFHN collaboration with DESE, DEEC, DTA and other agencies to continue to work on implementation of the Family Engagement Framework and support development of a new leadership structure for the State Family Engagement Coalition.
- DCYSHN programs will establish partnerships in the Haitian, Cambodian, and Vietnamese communities to better understand cultural differences for families of children with special health needs (both physical and behavioral) and develop strategies to increase awareness of services and reduce stigma.
- BFHN will continue support for the Vaccine Equity Initiative to promote COVID vaccination for children and families from diverse and underserved communities.
- Participation of the DCYSHN in the development and launch of the new state Caregiver Respite Line working with UMass Chan Medical School and the MA Office of Elder Affairs MassOptions program.
- Developmental screenings at all WIC offices using the CDC's "Learn the Signs. Act Early." Milestones Checklist.
- EI will continue to provide support for the Autism Insurance Resource Center at the UMass Medical School's Shriver Center.

- Promote the integration of social/emotional wellness into pediatric primary care by building on learning from past initiatives and implementing a new initiative funded by HRSA's Pediatric Mental Health Care Access program through partnership with the MA Child Psychiatry Access Project (MCPAP) and centering family engagement and equity.
- Support the resilience in students and the school community through School Based Health Centers (SBHC) staff who will respond to the collective trauma related to the COVID-19 pandemic. There will be continued emphasis on connecting with students and building a solid therapeutic alliance, which will be even more salient post-pandemic when students are more psychologically fragile. Clinicians will continue to assess for protective factors, including the presence of a trusted adult and school connectedness.
- Become part of existing interagency collaborations and activities and convene new collaborations as needed for a collective impact approach to enhance the system of mental health services at the state and community level. This will include DCYSHN collaboration with MassHealth on a tiered pediatric ACO Enhanced Care Coordination model for CYSHN and Total Case Management (TCM) benefit for children with medical complexity under its 1115 waiver renewal.
- DCYSHN will continue to work with the DPH Office of Preparedness and Emergency Management to promote emergency care planning.
- CICRF will develop community partnerships and cultural brokers to better understand the beliefs, behaviors and attitudes toward disease, treatment, mental health and community support for the Haitian and Cambodian/Southeast Asian families of CYSHN in the Greater Boston area.