

Federation for Children with Special Needs

Report on Feedback

from External Stakeholders

Amanda C. Green

Consultant

December 2023

# Executive Summary

According to stakeholders interviewed and surveyed for this study, the Federation for Children with Special Needs is appreciated, admired, respected, and even beloved.

* Staff are perceived as expert, helpful, and respectful of those they serve.
* Many stakeholders admiringly spoke of the Federation’s unique identity as “family-led and family-driven.”
* They commended the Federation’s support for family members to become advocates for their own children, and to become community leaders.
* Leaders of both government agencies and advocacy organizations spoke of the Federation’s excellent reputation, important services and resources, and value and influence as a partner.
* Multiple stakeholders enthusiastically commended the Federation’s services and supports for marginalized communities whose first language is not English.
* Many also admired the Federation’s ability to quickly pivot to online when the COVID pandemic precluded in-person work.

This study also revealed areas of challenge for the Federation.

1. **Insufficient Knowledge of the Federation**. Most stakeholders’ knowledge of the Federation was limited solely to the aspect of the Federation that directly affected them, usually pertaining to children and youth with disabilities. Very few fully knew what the Federation is and does.
2. **No Knowledge of the Federation.** Many stakeholders agree that the Federation is unknown to most families in Massachusetts, and they attribute this primarily to insufficiently effective outreach efforts.
3. **Loss of Uniqueness.** While some stakeholders extoled the Federation’s past achievements, they also expressed concern that the Federation currently risks losing its unique status as the pre-eminent organization in Massachusetts serving families of children with disabilities and special healthcare needs. New organizations with similar purposes are springing up locally and nationally, drowning out the Federation’s message. Old respected institutions are under fire in our society. Stakeholders believe the Federation must find a way to distinguish itself from others and shore up its reputation as a trusted authority.
4. **Mixed Views of Advocacy.** Some stakeholders feel that the Federation cannot vigorously and effectively advocate for families and children because it has a close relationship with state agencies and schools. By contrast, some stakeholders feel that the Federation wields power and influence *precisely because* it maintains good communication and collaboration with agencies and schools.
5. **Insufficient Presence “at the Table”.** Many stakeholders feel that the Federation should exert greater influence on statewide education, healthcare, and disability legislation and policy. They believe the Federation could make a far greater positive difference if it used its powerful voice more effectively.
6. **Insufficient Focus on Black Children**. While stakeholders admire the Federation’s extensive outreach to and services for diverse communities, some feel that the Federation should also focus more on black families and children, who are affected by well-documented systemic issues.
7. **Needs Exceed Capacity.** Stakeholders are aware that the needs are great, and that insufficient funding and inadequate staff capacity are a threat to the Federation.

Stakeholders also offered suggestions to address these challenges, and these are discussed in the full report.

# Method

### Interviews

Interviews via Zoom or telephone were conducted with 23 stakeholders from October 13 – November 3, 2023. For the interview questions, please see [Appendix A](#_Appendix_A:_Stakeholder). For the list of stakeholders, please see [Appendix B](#_Appendix_B:_List). Graphs of all responses to Question 6 can be found in [Appendix C](#_Appendix_C:_Stakeholder).

### Survey

A link to the online stakeholder survey was sent to registrants of the March 2023 Visions of Community conference and then posted for several weeks on the Federation’s website and advertised via email. For the survey questions, please see [Appendix D](#_Appendix_D:_Online). The seventy-nine stakeholders who responded to the online survey self-identified in these categories:

|  |  |
| --- | --- |
| Role | Number of Respondents |
| Parent or Guardian | 53 |
| Education Professional | 10 |
| Educational Surrogate | 8 |
| Education Advocate | 2 |
| Social Worker | 1 |
| Caregiver | 1 |
| Parent and Professional | 1 |
| Grandmother | 1 |
| Health and Wellness Navigator | 1 |
| Program Director of a Special School | 1 |
| TOTAL | 79 |

The online survey was offered in six languages: English, Chinese, Vietnamese, Portuguese, Spanish, and Haitian Creole.

# Findings

### Strengths

External stakeholders were expansive in their praise for the Federation as an organization with a storied history and a dynamic present. One stakeholder who has a long relationship with the Federation said, “The Federation is the Greatest of All Time, the original fire that brought special education to the country and the world.” Another said: “The Federation is an organization conceived of and founded by family members of people with disabilities and special health needs who found community with one another and felt the need to collaborate and coordinate to improve the quality of life for their children and families at a time when it was quite revolutionary. It has evolved into a vibrant sustained organization…that has distinct programs that address different pieces of the special needs puzzle for children and youth, filling gaps and surrounding kids and families with services.” A third said, ”The Federation is the premier front-runner as advocates for students with disabilities in the Commonwealth.” Another said, “The Federation is a coalition of different projects addressing and educating parents of kids with a wide variety of disabilities. The core of the Federation is parent empowerment and training and education.” And another said, “The Federation teaches parents how to advocate for their kids in many ways, not just in education. You learn so much you can apply to your kids and the community.”

The online survey correlates with favorable interview data. Of the 77 people who responded, 83 percent either strongly agreed or agreed that “the Federation offers services that help my family.”

A sizeable proportion of online survey respondents knew that the Federation trains parent-leaders in several languages and reaches out to diverse communities.

The online survey question “What is most important to you about the Federation?” attracted 69 responses indicating that **support and training for families** are the Federation’s most valued functions.

* Twenty-three percent of respondents said that support with special education is most important to them.
* Another twenty-three percent agreed that support is most important but did not specify a topic area. It is possible that some of these respondents may value special education support, in addition to support in other areas.
* Nineteen percent answered that training is most important to them. No other category garnered a significant response.

When asked what the Federation does very well, respondents gave 100 answers (the question permitted multiple responses).

* Fifty percent of responses indicated that the Federation does very well with **support and training for families**. Therefore, to survey respondents, what is most important about the Federation correlates to some extent with what they think the Federation does very well.
* Another 13 percent of responses called out the Federation’s strengths in **outreach to diverse populations**, whether through respecting diversity, employing cultural brokers, or offering workshops in multiple languages.
* Several other perceived strengths garnered a couple of points each, e.g., SEPAC support, the Educational Surrogate program, training for advocates, and conferences. Seven percent of responses commended the Federation’s systemic advocacy on a policy level.

Answers to two of the interview questions strongly align with online survey responses indicating that training for families and outreach to diverse families are strengths for the Federation.

Certain aspects of the Federation received specific praise from the stakeholders who were interviewed:

#### Staff who focus on outreach to diverse communities

* + “They are always acting on behalf of diverse communities. It’s not just words.”
  + “The Federation sees families. They don’t look at them with a deficit lens; they look at them as the rich resources and amazing talent they are bringing.”
  + “We learned about cultural brokers from the Federation. It was eye-opening! We had never heard of this role before.”
  + “The Federation is led by those with lived experience. Staff come from diverse communities, are bilingual, and are parents themselves, so they can help bring other parents up in their journey.”
  + “The Federation is always listening and trying to help. They never say no to me.”

#### Staff from the MA Family Engagement Center

* + “You cannot do family engagement work unless you know the population you are serving. They know the population and make sure they have the support in place to assist families. They are really effective.”
  + “The Federation brings together families, teachers, educators to be in the space together to think about how we will co-design, as opposed to ‘I’m telling you something and we’re going to do it.’”
  + “I thoroughly enjoy working with the Federation’s knowledgeable staff. They are very professional, a joy to work with. I know they will follow through when they say they will. I recommend them to districts, and I’m very pleased when I hear districts are working with them.”

#### Special education

* + “All the knowledge I have as a parent-professional is from the Federation.”
  + “I’ve been seeing a lot of parents coming out of their training who are now actively in the field of advocacy and actively helping families.”
  + “A strength is the Federation’s reputation. When you get a call from them, as a school person, you pay attention because they have the ability to cut through issues, and they know their business.”
  + “The Federation closes the power gap by educating parents and training advocates so the system is not so difficult and intimidating for parents.”
  + “I want to emphasize that my experience working with the Federation is that they really truly want to be partners. They want to help. They are always willing to come to the table with ideas, not just problems. At the center of everything they do is families and kids – and that’s not always true for every agency.”
  + “The Federation is respectful and responsive to differences of opinion around special education. I appreciate their collegiality and mutual agreement around the understanding that students with complex needs are all of our responsibility.”

#### Family Ties

* + “I recommend the Federation to my stakeholders primarily because of the deep expertise the Federation has with resources across the state.”
  + “Many people within the early childhood disability community recognize Family TIES as a trusted source of information.”
  + “Family TIES has good branding! Lean into that.”

### Challenges

1. **Insufficient Knowledge of the Federation**. Data from both the interviews and online survey clearly demonstrate that most stakeholders know with more or less specificity that the Federation is involved in special education, but stakeholders have detailed knowledge only about the aspect of the Federation that has directly affected them. In reality, the Federation is a *federation*. It is a union of many projects in the areas of education and health, serving parents/guardians of infants, children, and youth, as well as youth themselves, and school and healthcare professionals. Not limited to addressing “special needs” (a term several stakeholders recommended be discarded), the Federation assists all families, whether or not their children have disabilities or special healthcare needs. However, the breadth and depth of the Federation’s mission is a well-kept secret to most.

Seventy-four percent of those interviewed believe that the Federation’s principal emphasis is special education.

Eighty-two percent of 78 online survey responses show that stakeholders believe the Federation focuses mostly on special education.

Even if interviewed stakeholders work in another area, they were likely to discuss the Federation’s support for families of students with disabilities in special education. Only two of the 23 stakeholders *did not* mention special education during their interviews. By contrast, healthcare was mentioned only by stakeholders who work in that field.

When stakeholders were asked directly if the Federation serves all families, the “no” and “don’t know” answers outnumbered the “yes” answers.

Online survey responses showed a similar pattern but with 50 percent “don’t know” and 17 percent “false” answers.[[1]](#footnote-1)

Incomplete knowledge of the Federation’s work, even by its allies and clients, has serious implications.

* To fulfill its mission and to satisfy the terms of its funding, the Federation must serve large numbers of families and professionals. The less people know about the Federation, the less likely they will be to approach the Federation for services.
* Potential organizational allies and collaborative funding sources are less likely to partner with the Federation if they do not know what it does. The head of one large organization explicitly stated during their interview, “I don’t know fully what the Federation does or what its capacity is, so I don’t know how to leverage a partnership with the Federation.” Another leader said, “I would like to understand the Federation’s role better. I don’t know when I can or should reach out to them, unless I’m with a group they are already part of.” A third stated, “Why don’t I know more about the Federation? They need to get the word out about themselves.”

That said, the fact that so many are aware of the Federation’s historic and present role in special education is also a foundational strength for the organization, one upon which it can continue to build. It was clear from stakeholder interviews that much of the devotion people feel for the Federation springs from its work on behalf of children who have disabilities. One fervent stakeholder said, “I hope the Federation’s priority remains children with disabilities. Otherwise parents will have nowhere else to go. The Federation is truly the place to call if you don’t know who else to turn to. People are part of the Federation because of their passion for children of families with disabilities.” Another spoke of the fundraising potential and societal influence that can accompany disability work: “If you lay it out with a vision, disabilities can be a charmed path. Doors will open, relationships will come.”

1. **No Knowledge of the Federation.** Similar risks to the Federation apply if families and professionals across Massachusetts are completely unaware that it exists. If families or professionals have never heard of the Federation, they will not be served, and they cannot partner with or fund the Federation.

Stakeholders who were interviewed believe or suspect that the Federation is unknown to many.

One said, “The Federation needs better outreach! They are not reaching everyone they should be reaching. I wish I had known them when my son was younger. I live nearby. How come I didn’t know?” Another shared that they had worked as an educator in the center of the state for years but never heard of the Federation. Others said they were not aware of the Federation at all until the Massachusetts Department of Elementary and Secondary Education (DESE) recommended it. Another said, “The Federation is known by ‘people in the know’. Many new agencies and providers have never heard of it.”

Respondents to the online survey also suggested that the Federation needs more visibility in Western Massachusetts, the Cape, Central Massachusetts, and the North and South Shores. They recommended better outreach, including partnerships with pediatricians, provider agencies, and IEP Teams across the state, who could distribute Federation materials. One person interviewed suggested using the Special Education Parent Advisory Council (SEPAC) network to get the word out, as well as collaborating with organizations like The Arc. Several stakeholders also urged a stronger social media presence in different languages, and targeted emails that follow up when there is contact. But in addition, those from diverse communities asked that the Federation remember that not everyone is online, and that there is still a role for paper when it comes to reaching out.

1. **Loss of Uniqueness.** There was significant concern among stakeholders that the Federation must not rest on the laurels of the past but must find a way to become essential to a new generation of families and professionals. One flagged an [October 2023 *Boston Globe* article on special education](https://www.bostonglobe.com/2023/10/20/lifestyle/parents-guide-special-education-mindset/) that listed the Federation as merely one resource among numerous others, useful only because it offers “free basic rights online workshops.” [Understood.org](https://www.understood.org/) was the top resource, “as a user-friendly, civilian’s guide to special education,” and DESE was the place to go for information on the law. The Federation’s true identity as a one-stop shop was unknown.

During the interviews, two stakeholders observed that societal distrust of large organizations may drive people away from the Federation, while a plethora of information on the web about smaller and newer organizations means it is harder to get the message out.

One stakeholder candidly described their perception that the Federation has changed from an organization that once was “arm in arm with parents” to “a resource that leverages services to constituents in a homogenized way that is similar to what other organizations do” and that is “less accessible to individuals who need help because it’s migrating to become more of a corporation.” This stakeholder asks, “Does the Federation still actually work for parents, or are they more of a resource and a helpline that says if you have that problem, here’s a list to find someone over there?” This comment was echoed by one person on the online survey, who complained that they were “sent a laundry list of services that I'd already said didn't fit my family's needs. Just to give a response and cross me off the list.”

Another theme running through the interviews and to some extent in the online survey was the cost to the Federation of emphasizing online services at the expense of in-person ones. Several stakeholders complimented the Federation’s ability to pivot online when the pandemic arrived. Online services were widely applauded because they allow families to access resources at different times of day and in different languages. Yet some observed that online services are not accessible to all communities, and in-person services build strong emotional connections with the Federation. It was striking to this consultant that those who spoke most passionately about the Federation had had the most personal contact. Personal contact builds good will and loyalty to the organization, attracts donors, increases word-of-mouth, and enhances the organization’s reputation. One stakeholder said, “The humanity I see in the Federation, that’s what draws me near them. I ask myself, ‘What can I do in return? What can I do to support them?’” Another praised the people who had assisted her: “The Federation’s staff is good at the core, humble and helpful.” A third enthused, “Anything for the Federation!” A few noted the power of the in-person Visions of Community conference to build community and raise the Federation’s visibility.

One agency leader sounded a warning that less qualitative data from decreased personal contact increases the Federation’s reliance on quantitative data to justify its funding. However, if quantitative data is not collected and reported to a very high standard, or if it is not augmented by good qualitative data that tells a story, it may not be sufficiently compelling. This stakeholder cautioned that funding and support may be lost. “Qualitative data is harder to see if it’s not in person. The Federation needs to bring those who haven’t known them from forever into their orbit. Maybe invite them to participate in the day-to-day, as well as conferences, so their impact can be seen.”

Finally, stakeholders repeatedly mentioned one theme related to the Federation’s unique identity: the Federation’s special relationship with families. The Federation’s business is “family leadership development.” The Federation is “family-led and family-driven.” This is worth contemplating as the organization works to restore and maintain its unique place in the non-profit sector.

1. **Mixed Views of Advocacy.** Of the 23 stakeholder interviewed, seven believe that the Federation is “in the pocket” of schools and state agencies, especially DESE, and is therefore unable to speak truth to power and effectively advocate for families and children. By contrast, six stakeholders believe that the Federation is able to be effective *precisely because*it maintains good communication and collaboration with agencies and schools. One stakeholder in the latter camp said, “The Federation needs to continue its good relations with DESE. That’s a strength because they are seen as a partner, not an adversary. This helps build relationships to support all families, so there’s not ‘us and them’.” Another said, “The Federation strengthens family/district partnerships in our district.” One suggested that DESE and the Federation should jointly train advocates. Yet another advocated that the Federation partner more extensively with the Massachusetts Department of Mental Health, especially in a time when so many families and students are experiencing mental health challenges.

Speaking to the perception that the Federation is “so beholden financially to schools and agencies that it cannot fully be the voice of families and children,” one stakeholder offered an insight. They suggested that perhaps the Federation is not as aggressive as some would like it to be, because one of the Federation’s core strategies is advocacy through partnership rather than dispute. A principled stand, they observed, could look the same as fear of financial reprisal if the principles behind the stance are not articulated. They recommended that the Federation be up-front with its core values to mitigate misunderstandings.

On a related note, a few stakeholders expressed concern that some advocates who are Federation-trained assume an aggressive posture at the IEP table, and that this does not serve families well. On the one hand, the Federation itself is perceived as making change through communication and collaboration; on the other, a number of advocates who complete the Parent Consultant Training Institute (PCTI) choose to be combative, and the Federation becomes associated with their actions. Stakeholders recommend that the Federation examine its policies and practices regarding advocacy training, to protect its reputation, improve training, and improve the system of family support. One stakeholder went further, suggesting, “It’s not right that the Federation is helping advocates make money off of families. Instead, train advocates to train families and walk alongside them.”

1. **Insufficient Presence “at the Table”.** Those who answered the online survey, many of whom are parents, assume the Federation has a seat at the policy table and is working for them.

However, stakeholders who actually sit at the policy table said in their interviews that they do not see the Federation nearly enough. As one said, “I don’t see the Federation in working groups or at the table when legislation is filed. They tend not to be a stakeholder group in general education conversations. The Federation could be a supportive, strong advocate for the increased resources and funding generally that schools need, as well as for special education.” Another said, “To be the most important family engagement organization in Massachusetts, the Federation would need to be at every policy table, they’d be talking to agencies about policy, they’d be meeting with the legislature, they’d be engaging with more families. I don’t see them.” A third recommended, “The Federation should organize families to go to the statehouse to advocate so that there can be more robust services for children with special healthcare needs. Get on legislators’ schedules and visit them! Create partnerships with those who have power and influence!” A fourth person said, “The Federation should be more active in government affairs and partner with other disability organizations around law and policy. They should be a voice against rising racism and a leader in embracing neurodiversity without succumbing to ableism. Be a social justice voice.” Yet another emphasized the importance of connecting with legislators’ hearts and minds. “Politicians need to know that – outside financial obligations – students with disabilities are humans, the most vulnerable kids in our districts. It goes well beyond dollars. It’s not just a legal requirement; students truly need special education to live.”

1. **Insufficient Focus on Black Children and Youth**. Nearly all stakeholders who were interviewed, as well as many respondents to the online survey, highlighted the Federation’s notable expansion of outreach and services to diverse families who speak multiple languages. Stakeholders expressed a great deal of warmth and admiration for these efforts, and suggested that the Federation could assume an even greater leadership role, in partnership with other organizations, in light of the migrant crisis.

However, stakeholders believe that the Federation is directing insufficient attention to the needs of African American families. Said one stakeholder, “The Federation keeps turning to different issues – immigrants or autism, for example – but never dealing with the issues of black students. I understand it’s important to address the needs of English Learners, but why can’t there be a focus on black students at the same time?” Another said, “The Federation is not helping black parents be equal partners in the special education system that has never treated them equally.” A third said, “The Federation should do more outreach and build connections with people who are not always called upon,” and also pointed to the Federation’s internal operations: “The Federation does not employ enough diverse staff or recruit enough diversity, especially black diversity, on its Board.”

1. **Needs Exceed Capacity.** Stakeholders are quite sympathetic to the push-and-pull between needs and resources. One said frankly, “They are trying to do too much.” Another, “The needs are many, and they don’t have the capacity to address everything.” A third, “ The Federation needs more staff. They can’t be everywhere at once.” “Attracting and retaining good people is one of their great challenges,” said another. Nearly all stakeholders identified lack of funding, and the continuous need to search for funding, as an ongoing threat to the Federation’s operations. One stakeholder observed that if it were easier to know what the Federation does (see bullet #1), then other organizations would be more likely to reach out to the Federation to braid funding and cost-effectively leverage their combined power.

Signs that the Federation is over-extended were apparent in both the interviews and online survey. From the survey:

* “I have asked questions via email, and no one replied back to me.”
* “I feel that setting up a better directory and communication lines would be very helpful.”
* “Return phone calls.”
* “The website is somewhat clunky and the links are sometimes out of date.”
* “Please please ANSWER the phone....it is so difficult to get a hold of a human.”
* “Better respond to those who call in, especially those speaking different language. Better collaborate among all projects as I hate to repeat my own stories whenever I talk to a different person from different project.”

A stakeholder who was interviewed echoed the survey recommendation that the Federation’s systems should be organized so that callers can make just one phone call and receive a comprehensive intake. Not only would they not need to repeat themselves, they could also be connected to wrap-around services in every category that fulfills their need. From the Federation’s standpoint, this would increase efficiency. The Federation is and should be perceived as a one-stop shop.

### Conclusion

As its 50th anniversary approaches in 2024, the Federation for Children with Special Needs finds itself in a position to reflect on and reassess what impact it has made, is making, and hopes to make in the future for Massachusetts families. It has the opportunity to examine its policies and practices to put hope into action. As this report confirms, the Federation boasts a powerful legacy and very significant strengths to draw upon. It also has barriers to overcome and decisions to make about the road ahead.

# Appendix A: Stakeholder Interview Questions

1. In your own words, **what** is the Federation for Children with Special Needs, and **what does it do**?
2. From your perspective, in what ways is the Federation **effective**?

In what ways is the Federation **ineffective?**

1. On a scale of 1 to 5, with 1 being least effective and 5 being most effective, how effective do you think the Federation is?
2. Do you recommend the Federation to your stakeholders? Why/why not? [*Asked only if applicable or if not covered in responses to previous questions.*]
3. How could the Federation have a bigger positive impact?
4. Do you agree or disagree with the following statements?

|  |  |
| --- | --- |
| The Federation: | YES/NO/DON’T KNOW |
| is mostly focused on special education. |  |
| is the most important family engagement organization in Massachusetts. |  |
| is focused on racial equity. |  |
| provides valuable training for school personnel. |  |
| provides valuable training for families. |  |
| effectively supports diverse families who speak multiple languages. |  |
| is well known/recognized by most families across Massachusetts. |  |
| trains special education advocates who are professional and effective. |  |
| is perceived as a productive partner by *school professionals* in Massachusetts. |  |
| is perceived as a productive partner by *advocacy organizations* in Massachusetts. |  |
| is perceived as a productive partner by *medical and public health professionals* in Massachusetts. |  |
| is respected by Massachusetts government officials and the legislature. |  |
| Influences state policy. |  |
| helps all families, even if their children don't have special needs |  |

1. Can you tell me more about any statements above that you **did not** agree with?
2. Is there anything in the political, economic, or sociocultural landscape that you think could be a **threat** or **opportunity** for the Federation? If so, could you elaborate on that?
3. What should I have asked that I didn’t ask?

# Appendix B: List of Stakeholders Interviewed

Asha Abdullahi, Somali Parents Advocacy Center for Education

Edith Bazile, Black Advocates for Educational Excellence

Oanh Bui, Massachusetts Department of Public Health

Jamie Camacho, Massachusetts Department of Elementary and Secondary Education

Carol Curtin, Eunice Kennedy Shriver Center at UMass Chan Medical School

Jennie DunKley, Advocate

Elaine Gabovitch, Massachusetts Department of Public Health

Darla Gundler, UCONN Early Childhood Personnel Center

Daniel Heffernan, Kotin, Crabtree, and Strong

Carla Jentz, Administrators for Special Education

Anna Krieger, Massachusetts Advocates for Children

Rhonda Mencey, Advocate

Cory Mikolazyk, Foxborough Public Schools

Kimberlee Powers & Tina Hoofnagle, Lynn Public Schools

Soraya Presume, Brockton Public Schools

Raquel Quezada, Cambiando el Mundo de Personas con Discapacidad

Pam Sager, Parent/Professional Advocacy League

Leo Sarkissian, The Arc of Massachusetts

Tom Scott, Massachusetts Association of School Superintendents

Samantha Storey, Special Needs Advocacy Network, Inc.

David Valade, Massachusetts Department of Elementary and Secondary Education

Emily White, Massachusetts Department of Public Health

Toni Wolf, Massachusetts Rehabilitation Commission

# Appendix C: Stakeholder Interview Responses to Question 6

# Appendix D: Online Survey Questions

1. What is your role?
2. How did you hear about the Federation for Children with Special Needs?
3. For how many years have you interacted with the Federation for Children with Special Needs?
4. Please tell us if you think the following statements about the Federation are true or false.

**The Federation:**

* 1. is mostly focused on special education.
  2. helps families with children who are 0 – 3 years old.
  3. teaches professionals how to partner with parents.
  4. helps all families, even if their children don’t have special needs.
  5. is focused on racial equity.
  6. influences state policy.
  7. trains parents to be leaders.
  8. reaches out to diverse communities.
  9. helps parents find the right school for their child.
  10. answers questions about health insurance.
  11. trains special education advocates.
  12. Connects parents to other parents who can give them support.
  13. partners with schools and healthcare organizations so that services for families improve.
  14. offers trainings in several languages.

1. Please tell us how strongly you agree or disagree with these statements.
2. The Federation offers services that help my family.
3. The Federation advocates for my children’s rights.
4. If the Federation were not here, my child’s education would suffer.
5. If the Federation were not here, my child’s health would suffer.
6. Massachusetts government officials respect the Federation.
7. Massachusetts schools respect the Federation.
8. Massachusetts health professionals respect the Federation.
9. I understand what the Federation does.
10. What is most important to you about the Federation? Please tell us just one thing.
11. In your opinion, what does the Federation for Children with Special Needs do very well? Please tell us no more than two things.
12. In your opinion, how could the Federation improve? Please tell us no more than two things.

# Appendix E: Additional Online Survey Data

1. The online survey also asked a series of project-specific questions, which revealed varying levels of respondent knowledge. For additional information on these questions, please see [Appendix E](#_Appendix_E:_Additional). [↑](#footnote-ref-1)