Mass General Brigham Mass General for Children Down Syndrome Program Massachusetts General Hospital Founding Member, Mass General Brigham

The Massachusetts General Hospital Down Syndrome Program conducted a two-year study (2021–2022) of the barriers and facilitators that Black and/or Spanish-speaking families encounter when accessing healthcare for their loved ones with Down syndrome. The full reports are available in English and Spanish.

We encourage all Down syndrome organizations to take the following next steps:

- Ask your staff and Board to read and discuss the report.
- Engage in dialogue with your members about what results resonate with them and what recommendations can be implemented together.
- Generate awareness and conversation online by using any of the sample social media posts below.
- Consider creating a Diversity Task Force at your organization to address the needs of your diverse community members.

Best,

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Introduction of Social Media Posts
Here is an example of how your organization might choose to post our results. Feel free to customize to your needs.

[ORGANIZATION NAME] received the results of a national survey on access to care for Black and Spanish-speaking families. Here's just one thing we learned from the survey: [CHOOSE ANY RESULT FROM BELOW]. Read the full survey results in English or Spanish and help us spread the word on these important issues by sharing this post or telling us about your experiences in the comments.

All of the graphics and figures can be found in English at https://drive.google.com/drive/folders/1qlJUJYoPX8_g5bWB01sTADMvQ5OR1m7-?usp=sharing

General Results to Include in Social Media Posts

Primary care providers reported that more care coordination is needed to provide high quality care for patients with Down syndrome from Black or Spanish-speaking families and more social workers on site are necessary.

Primary care providers said that lack of time is a barrier to providing first-rate healthcare to patients with Down syndrome from Black or Spanish-speaking families. Primary care providers also cited that families' lack of access to the medical system continues to be a barrier to high quality care.

One resource that primary care providers found helpful for the management of patients with Down syndrome are the AAP Healthcare Guidelines on Down syndrome.

Results for Black patients with Down syndrome *link to individual pictures

For each of the following blurbs, use graphic: Figure 2

A recent survey shows that about half of caregivers of Black patients with Down syndrome felt that their loved ones receive lower quality medical care than their white counterparts with Down syndrome.

For each of the following blurbs, use graphic: Figure 3

About one quarter of caregivers of Black patients with Down syndrome have felt that their loved ones with Down syndrome were treated with disrespect because of their ethnicity or race, and one quarter felt the same because of their loved one's disability.

For each of the following blurbs, use graphic: Figure 4

About half of caregivers of Black patients with Down syndrome said that it is important for clinicians to share their same religious or cultural beliefs, and about one third felt it is important for clinicians to be of the same gender as their loved one with Down syndrome.

For each of the following blurbs, use graphic: Figure 5

Some of the main healthcare worries of caregivers who have Black patients with Down syndrome were taking time off work, being concerned that their loved one would be treated with respect, and out-of-pocket medical costs.

For each of the following blurbs, use graphic: Figure 6

When searching for information on Down syndrome, about half of caregivers of Black patients with Down syndrome felt frustrated in their search, and about another half felt that it took a lot of effort to find that information.

For each of the following blurbs, use graphic: Figure 7

About 84% of caregivers of Black patients with Down syndrome felt somewhat confident about their ability to find information on Down syndrome if needed.

For each of the following blurbs, use graphic: Figure 8

According to caregivers of Black patients with #Downsyndrome the most trusted messengers of healthcare information are doctors, hospital or clinic web pages, and charitable organizations.

No Graphic

Many caregivers of Black patients with Down syndrome said that they look to other parents and caregivers, as well as support groups, for advice and information. One caregiver commented, “For me, there’s this support group… We share experiences, build each other, and share emotions, and help each other deal with different situations.”

For each of the following blurbs, use graphic: Figure 9

Two-thirds of caregivers shared that the COVID-19 pandemic had a serious effect on the ability of people with Down syndrome from Black families to connect with friends and family.

No Graphic

Primary care providers emphasized the importance of forming trust with families who have a Black patient with Down syndrome. One PCP said, “the thing that facilitates trust is regular follow-up, not letting anything slide, reaching out to them by phone or asking them to come into clinic if need be, making sure that none of their concerns are just left hanging.”

Primary care providers should encourage caregivers with a Black patient with Down syndrome to ask questions, while being careful to listen to their specific needs to facilitate trust. One PCP stated, “We ask them, ‘What concerns do you have? What questions do you have?’ And that’s how we open the door.”

Primary care providers emphasized the importance of longitudinal care for Black families with a patient with Down syndrome. A PCP said, “So if they could have a provider that would stick with them for many years, I think that’s really, really ideal when you’re dealing with chronic issues.”

From the perspective of primary care providers, a barrier for Black families who have pateints with Down syndrome is sometimes medical literacy. One PCP commented, “We forget that patients are born to parents who they themselves might have medical issues that prevent them from having a high health literacy.”

PCPs noted that another barrier for Black families who have patients with Down syndrome are cost barriers. One PCP remarked, “how you access the healthcare is unequal because of how much money you have and how much support.”

A barrier for Black families who have patients with Down syndrome, noted by primary care providers, is transportation. One PCP said, “...if you live in the middle of a state you basically have to drive four or five hour to get any sort of pediatric care.”

According to primary care providers, a barrier for Black families with loved ones with #Downsyndrome is competing demands on the caregiver. One PCP stated, “But she has, I don’t know, three other kids and single mom and it’s very hard to get her son to all of the subspecialists’ appointments.”

Many caregivers with Black patients with Down syndrome noted that a facilitator of trust in the medical system is their physician having racial and ethnic concordance with their loved one. One caregiver noted, “I think I might just abandon everything else to go and check this person out if I found out that they were a physician of color who also had a child with Down syndrome.”

According to caregivers with Black patients with Down syndrome, a facilitator of trust in the medical system is high quality, compassionate specialty care. One caregiver commented, “I really want to make sure that we have access to equitable care, knowledgeable staff as far as physicians, and resources that are sometimes out of our county.”

Caregivers with Black patients with Down syndrome noted that recommendations for primary care providers from parents in similar situations facilitate trust. One caregiver stated, “For me, I do rely very heavily on recommendations … I was asking moms that I had recently met for pediatricians.”

One facilitator of trust touched on by caregivers with Black patients with Down syndrome was a strong relationship between providers and caregivers. Said one caregiver, “If you're comfortable, if you feel they’re accessible, and if you feel that you can get honest answers and ask them questions when you need it and that they genuinely care about your child, that’s very big.”

Some caregivers who have Black patients with Down syndrome shared that healthcare providers have been dismissive and underestimated the potential of their loved one with Down syndrome. Said one parent, "I've run into several providers who are giving information and making assumptions based on just what I find to be old data and inaccurate data."

Another issue for caregivers who have Black patients with Down syndrome is that insurance and medical-related costs can be roadblocks to care. One caregiver commented, “I don’t understand how they label these prices for families that are already dealing with possibly more healthcare costs than other families.”

Many caregivers who have children with Down syndrome faced discrimination based on their child’s race in the healthcare setting. One caregiver said, "I find that sometimes as a woman of color, as a Black woman, when I walk into healthcare facilities, there are some assumptions about what [my child] should and could receive.”

Results for patients with Down syndrome coming from a Spanish-speaking family

For each of the following blurbs, use graphic: Figure 10

About one-third of caregivers from Spanish-speaking families felt that patients with Down syndrome who do not speak English receive lower quality medical care than most white patients with Down syndrome.

About 29% of caregivers from Spanish-speaking families felt that patients with Down syndrome who are Latino/a receive lower quality medical care than white patients with Down syndrome.

For each of the following blurbs, use graphic: Figure 11

Within the past year, 12% of these caregivers have felt that their patient with Down syndrome was treated unfairly because of their race or ethnicity in a medical setting, and 10% felt the same because of their loved one's disability.

For each of the following blurbs, use graphic: Figure 12

About 39% of caregivers with a patient with Down syndrome who is from a primarily Spanish-speaking family felt it is important for clinicians to be from the same racial or ethnic background as their loved one.

About one quarter of caregivers with a patient with Down syndrome who is primarily Spanish-speaking felt it is important for clinicians to share the same cultural beliefs.

About one-third of Spanish-speaking caregivers with a patient with Down syndrome felt it is important for clinicians to be the same gender as their loved one with Down syndrome.

For each of the following blurbs, use graphic: Figure 13

About 59% of Spanish-speaking caregivers worried about taking time off work to attend their patient's medical tests and appointments, and 54% worried that their loved one with Down syndrome will be treated with respect.

When their patient was referred for a test or appointment, about one-third of Spanish-speaking caregivers worried about being treated with respect themselves, and about one half worried about the associated out-of-pocket expenses.

For each of the following blurbs, use graphic: Figure 14

When searching for information on Down syndrome, about one-third of Spanish-speaking caregivers felt some degree of frustration in their search, and about one quarter shared that it took a lot of effort to find that information.

For each of the following blurbs, use graphic: Figure 15

About half of Spanish-speaking caregivers felt at least somewhat confident that they could get information on Down syndrome if they needed it.

For each of the following blurbs, use graphic: Figure 16

According to a recent study, the most trusted messengers of healthcare information for Spanish-speaking caregivers with a child with Down syndrome are: doctors, the Internet, and hospital web pages.

No Graphic

Some Spanish-speaking caregivers who have a child with Down syndrome said that caregiver support groups were a trusted source of information. One caregiver said, “Here, locally, there are several groups, there is the Down Syndrome Guild in Dallas and there is another one for the south which is in Fort Worth, and it helps a lot, they help a lot.”

Spanish-speaking caregivers who have a child with Down syndrome stated that Down syndrome resources were trusted sources of information. One caregiver said, “Obviously, I have been in communication with the national Down Syndrome Society. I know the great support they give, and they are also always on par to give that support.”

For each of the following blurbs, use graphic: Figure 17

About half of Spanish-speaking caregivers with a patient who has Down syndrome relayed that the COVID-19 pandemic had at least a somewhat serious impact on their loved one’s ability to connect with friends and family.

No Graphic

Primary care providers have said that racial, ethnic, and language concordance facilitate trust for Spanish-speaking families, and when the PCP does not speak Spanish, an in-person interpreter is appreciated. One PCP commented, “I think it’s just-there’s more trust if it comes from someone who’s a native Spanish speaker or somebody who’s African-American. You feel more heard.”

Something that primary care providers can do to help Spanish-speaking families with a patient who has Down syndrome is to help them navigate beyond the PCP office, like helping them schedule testing and specialist appointments. One PCP said, “I think that sometimes they may have difficulties with scheduling appointments and so we try to work around that by scheduling them for them.”

A barrier for Spanish-speaking patients and families is language in settings beyond the PCP office. One PCP said, “And then additionally, when the subspecislist’s office or the therapist’s office calls them, they have a really hard time communicating. There’s much less cultural integration with smartphones and computers.”

Primary care providers found that another barrier faced by these Spanish-speaking families is distrust of service providers or other government programs. Said one PCP, “I think trust comes more and I have patients afraid to sign up for resources because of the whole issue of whether their citizenship would be threatened if they signed up for food stamps or any kind of services like that.”

Many PCPs reported that barriers for Spanish-speaking families with a patient with Down syndrome are difficulties in navigating education materials and websites that are only available in English. One PCP noted, “You can say like, ‘Look up this website,’ but some families, I mean, some of my caregivers don’t know how to google. And then, again, finsiding appropriately translated information right, because that’s the other big part too.”

According to Spanish-speaking caregivers who have a child with Down syndrome, health care providers should focus on the patient instead of their Down syndrome diagnosis to facilitate trust. Said one caregiver, "Whenever you are going to deal with a family of a child with Down syndrome, do as if it were your own child, just as you would like to be cared for."

Spanish-speaking caregivers who have children with Down syndrome said having providers who were knowledgeable & empathetic was important. One caregiver said, “I think we all agree that the pediatrician should be someone who… has tact to tell us things, also that it is - but who shows that empathy, that does not show that fear of our daughters.”

According to Spanish-speaking caregivers who have a child with Down syndrome, trust in a provider is built with the first conversation about Down syndrome. One caregiver said, “That is a moment where, instead of wanting bad news, I would like to be explained what it means to have the blessing that we have.”

Spanish-speaking caregivers who have children with Down syndrome felt that language barriers often get in the way of their communication with primary care providers. One caregiver mentioned, “But even I, who speaks English, sometimes feel lost… It’s very sad because… we all deserve more, no matter what color your skin is, whether you speak English or not.”

Spanish-speaking caregivers who have children with Down syndrome shared that they often have to deal with social isolation from their families and stress. One caregiver said, “We kept the secret until my baby was leaving the hospital, and that was hurting us a lot. Nobody wanted to tell the family… Because thinking that people would reject me.”

Spanish-speaking caregivers who have children with Down syndrome shared that they sometimes encounter condescending, discriminatory treatment from people in a medical setting. Said one caregiver, “But I have lived it and there are some my family friends have lived it, the discrimination is double, it is double because of disability and because of your race.”

Take-home messages from our report

Research shows that relationships built on trust are crucial for establishing long-lasting medical care.

Research shows that more physicians of color are needed to take care of patients with Down syndrome.

Research shows that caregivers are looking for medical providers who demonstrate a willingness to learn more about Down syndrome.

Research shows that how professionals deliver the initial diagnosis of Down syndrome can have a long-term impact on caregivers’ capacity to trust the health care system.

Research shows that it takes a funded village. Caregiver mentioned that healthcare professionals are their top sources of trusted information.

Research shows that cultural humility and competency need to be part of continual education for the healthcare system.

Research shows that the medical community needs to recognize that raising a child with Down syndrome can be hard.

Research shows that some caregivers are tired of being reminded by the medical community about their race.

Research shows that structural barriers and systemic racism can become heightened with a diagnosis of Down syndrome.