






## ORIGINAL ARTICLE

# Healthcare experiences of patients with Down syndrome from primarily Spanish-speaking households

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## Abstract

We report on the health care experiences of individuals with Down syndrome (DS) from families who are primarily Spanish-speaking. Data were collected through three methods: (1) a nationally distributed, 20-item survey, (2) two focus groups with seven family caregivers of individuals with DS who self-identified as living in primarily Spanish speaking households, and (3) 20 interviews with primary care providers (PCPs) who care for patients who are underrepresented minorities. Standard summary statistics were used to analyze the quantitative survey results. Focus group and interview transcripts, as well as an open-ended response question in the survey, were analyzed using qualitative coding methods to identify key themes. Both caregivers and PCPs described how language barriers make giving and receiving quality care difficult. Caregivers additionally described condescending, discriminatory treatment within the medical system and shared feelings of caregiver stress and social isolation. Challenges to care experienced by families of individuals with DS are compounded for Spanish-speaking families, where the ability to build trust with providers and in the health care system may be compromised by cultural and language differences, systemic issues (lack of time or inability to craft more nuanced schedules so that patients with higher needs are offered more time), mistrust, and sometimes, overt racism. Building this trust is critical to improve access to information, care options, and research opportunities, especially for this community that depends on their clinicians and nonprofit groups as trusted messengers. More study is needed to understand how to better reach out to these communities through primary care clinician networks and nonprofit organizations.

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## 1 | INTRODUCTION

Down syndrome (DS) is the most common genetic cause of intellectual disability, occurring in all race and ethnicity groups (de Graaf et al., 2015). Most patients are at additional risk for multiple chronic conditions over their lifetime, including congenital heart disease, thyroid conditions, gastrointestinal disorders, leukemia, obstructive sleep apnea, and accelerated aging, among others (Bull et al., 2011). Being under the care of knowledgeable clinicians and having access to care and services are essential for people with DS, as their life expectancy increases (Presson et al., 2013). Previous studies, however, have demonstrated that patients with DS, predominantly under the care of primary care providers (PCPs), are adherent to only 10%–67% of recommended national guidelines for screening and preventative health (O'Neill et al., 2018; Santoro et al., 2016; Skotko et al., 2013), suggesting that health equity (Krahn & Fox, 2014) by these markers at least, remains elusive.

The preponderance of evidence across a variety of health conditions suggests that this unfortunate reality is likely even worse for families who are Hispanic (Derrington et al., 2013; Flores & The Committee on Pediatric Research, 2010; Wang et al., 2015; Zuckerman et al., 2018) and those who have limited English proficiency (Betancourt & Tan-McGrory, 2014; Eneriz-Wiemer et al., 2014; Levas et al., 2011). At least part of what is driving these disparities are differences in the availability of and access to important health information, care services, and up-to-date resources. In this research team's own experience recruiting for a national randomized controlled trial studying the effectiveness of a novel web-based tool created for English- and Spanish-speaking caregivers of individuals with DS (Chung et al., 2021), only two Spanish-speaking families were ultimately enlisted for the study. This was despite the collaborative persistence of community-based nonprofit organizations and Spanish-speaking caregiver partners spreading news of the opportunity via social media, e-newsletters, and word-of-mouth over more than 9 months. In contrast, 355 caregivers—nearly all English-speaking—responded to the recruitment within 1 week, well above the intended 200 participant recruitment goal.

The alacrity with which white (non-Hispanic and Hispanic), English-speaking caregivers responded to the study—compared to the near nonexistent representation from the Spanish-speaking community—reflects a disparity in clinical research participation noted across communities with limited English proficiency (Alhalel et al., 2022; Cavazzoni et al., 2020; Egleston et al., 2015) and more generally, the deeper limitations of suggested approaches to outreach to

and share information with these diverse communities (NYU Langone Health Office of Science and Research, Clinical and Translational Science Institute, 2022) that are further affected by rare conditions. While more has been published related to disparities in access to care and health outcomes among individuals with limited English proficiency broadly (Foiles Sifuentes et al., 2020), and Spanish-speakers specifically (Fiscella & Sanders, 2016; Oh et al., 2020), we were not able to identify any working paper, guidelines, or research publication that explores the care experiences of and access to health information in this subset of the DS community.

The purpose of this research was to connect with primarily Spanish speaking family caregivers of individuals with DS and the PCPs in the community who care for them. We aimed (1) to identify the barriers and facilitators Spanish-speaking families of individuals with DS face when accessing health care and health information, and (2) to elicit sustainable pathways that are culturally sensitive and appropriate to engage with primarily Spanish speaking families.

## 2 | MATERIALS AND METHODS

This study was part of a larger effort to identify healthcare disparities for underrepresented minorities in the DS community. Methods used and the results related to healthcare experiences of patients with DS who are Black, African American, of African descent, or of mixed race have been detailed and reported by Krell et al. (2022). Methods are briefly summarized in this paper; any differences in methodology that were specific to this population are highlighted.

### 2.1 | Project leaders

The project team included clinicians and researchers from or affiliated with the Massachusetts General Hospital Down Syndrome Program (MGH DSP); a Diversity Outreach Specialist (A.P.); key stakeholders including expert advisors from the LuMind IDSC Down Syndrome Foundation and the Massachusetts Down Syndrome Congress (MDSC); five caregivers, of which two were Spanish-speaking (S.B., D.M.) caregivers who have a loved one with DS living in the United States; and five PCPs who care for Black/African American and/or Spanish-speaking people with DS in the United States. Of the PCPs, three are Spanish speakers (A.P., N.S., C.T). The team was complemented by a survey methodologist from the MGH Mongan Institute.

## 2.2 | Participants

Caregivers living in the United States with a son or daughter with DS who self-identified as being a primarily Spanish-speaking household were invited to participate in focus groups and/or complete an online or paper survey.

PCPs practicing in the United States with at least one patient with DS who is Black/African American and/or Spanish-speaking were invited to participate in the PCP interviews. PCPs could be physicians, nurse practitioners, or physician assistants (associates).

## 2.3 | Data collection

Data were collected from (1) individual PCP interviews conducted by a member of our research team over a 30-min Zoom meeting, (2) a novel, 20-item, Spanish-language caregiver survey ([Supplementary Materials Sections 1 and 2](#)) drawn from validated survey instruments distributed online and by mail, and (3) caregiver focus groups conducted over an hour-long Zoom meeting moderated by a Spanish-speaking member of the research team (K.K.). All focus groups and PCP interviews were recorded with permission. Informed consent was obtained verbally from all participants prior to participation in focus groups and interviews. Survey participants were required to review and acknowledge an informational page before proceeding with the survey; written informed consent was waived.

Caregiver survey items were developed in consultation with Dr. Karen Donelan, ScD, EdM, Director of Survey Research at the MGH Mongan Institute and adapted from validated survey instruments including the National Institute of Health's Health Information National Trends Survey (National Cancer Institute, [n.d.](#)) and the Agency for Healthcare Research and Quality's Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician & Group Survey 3.0 (Agency of Healthcare Research and Quality, [n.d.](#)), and the NIH Coronavirus Impact Scale (Stoddard et al., [2023](#)). The survey also included a single free-text question: "How has race and/or ethnicity impacted the care for your loved one with Down syndrome?"

The survey was presented in either English or Spanish depending on how the respondent answered the first question, displayed in both languages: "Which is the primary language spoken in your home?" or "Cuál es el idioma principal que se habla en su hogar?" If "Español" ("Spanish") was selected in the response, this question was followed by a second eligibility question: "Es usted padre, madre o cuidador de una persona con síndrome de Down?" ("Are you the parent or caregiver of a person with Down syndrome?"). A caregiver was determined to be eligible to complete the survey as a Spanish-speaker if the responses to these second question was "Sí" ("Yes").

The caregiver survey instrument, topic guide for the caregiver focus groups, and topic guide for the PCP interviews were developed in close collaboration with our physician, caregiver, and advocacy stakeholders. Study data were collected and managed using REDCap electronic data capture tools hosted at Massachusetts General Hospital (Harris et al., [2009](#), [2019](#)).

## 2.4 | Recruitment

### 2.4.1 | Caregiver focus group

Caregivers were recruited mostly through Spanish-language advertisements ([Supplementary Materials Section 3](#)) on the social media pages, newsletters, and e-newsletters from the MGH DSP, MDSC, and LuMind IDSC Down Syndrome Foundation. Advertisements were also posted on the principal investigator's (B.S.) personal social media accounts and shared through caregiver working group members' personal networks (social media and word of mouth). Caregivers who had previously participated in a research project with the MGH DSP in the past and noted that they would like to hear about future projects were also invited. Any person invited via social media or newsletters was asked to complete a screening survey to determine their eligibility ([Supplementary Materials Section 4](#)). Any communications related to logistics or procedure (both spoken and written) were conducted in Spanish when needed (K.K., D.M.).

### 2.4.2 | Caregiver surveys

All of the recruitment methods employed for the caregiver focus groups were used to post survey-specific Spanish-language advertisements ([Supplementary Materials Section 5](#)). Additionally, invitations were sent to 321 DS nonprofit organizations; the NIH's DS-Connect<sup>®</sup> registry, which serves as a central place for families to receive information about research studies related to DS; and to all Mass General Brigham patients with DS identifying as Spanish-speaking whose caregivers have access to the patient portal. Surveys were distributed online; nonprofit organizations were given the additional opportunity to request paper copies of the survey in Spanish ([Supplementary Materials Section 2](#)) for caregivers who may not have access to a digital device or the Internet, or preferred to complete the survey on paper.

### 2.4.3 | PCP interviews

PCPs were recruited from the same social media platforms as described above. The research team also made personal outreach by e-mail and telephone to eligible PCPs. Our team also contacted 13 major clinician organizations detailed by Krell et al., but these organizations either declined to participate or did not respond to our repeated requests.

## 2.5 | Analyses

Qualitative and quantitative analysis plan has been previously described by Krell et al. ([2022](#)). Audio recordings from the Spanish-speaking focus groups were first transcribed into Spanish (through TranscribeMe) and then translated into English prior to analysis with Dedoose, version 9.0.17.

**TABLE** Demographics.

Caregiver focus groups ( 7)	Number of participants	of participants
Gender of person with Down syndrome represented by caregiver		
Male	2	28.6
Female	2	28.6
Unknown	3	42.9
Race of person with Down syndrome represented by caregiver		
White	7	100
Ethnicity of person with Down syndrome represented by caregiver		
Hispanic	7	100
Age of person with Down syndrome (years) represented by caregiver		
0–4	1	14.3
5–12	1	14.3
13–20	2	28.6
21 or older	0	0
Unknown	3	42.9
Caregiver race		
White	7	100
Caregiver ethnicity		
Hispanic	7	100
Caregiver relationship to person with Down syndrome		
Mother	7	100
US region where caregiver resides		
West	0	0
Midwest	0	0
Northeast	2	28.6
South	2	28.6
Southwest	1	14.3
Unknown	2	28.6
PCP interviews ( 20)		
PCP gender		
Male	1	5
Female	19	95
PCP race		
Black/African American	3	15
White	12	60
Multirace	2	10
Asian	2	10
Unknown	1	5
PCP ethnicity		
Hispanic/Latino(a)	7	35
Non-Hispanic	13	65
US region where PCP practices medicine		
West	10	50
Midwest	3	15
Northeast	5	25
South	0	0
Southwest	2	10

**Spanish-speaking caregivers ( 41)**

Relation to the person with DS		
Mother or step-mother	28	68.3
Father or step-father	3	7.3
Sibling, half-sibling, or step-sibling	2	4.9
Blank	1	2.4
Race of caregiver		
Black/African American	0	0
White	13	31.7
Native American or Alaska Native	0	0
Multirace	5	12.2
Other	15	36.6
Blank	8	19.5
Hispanic, Latino/a, or Spanish origin		
No	0	0
Yes	34	82.9
Blank	7	17.1
Caregiver's last grade completed		
More than college	6	14.6
College graduate (B.S. or B.A.)	10	24.4
Some college or technical/vocational school	7	17.1
High school graduate (grade 12 or GED)	6	14.6
Some high school	4	9.8
Blank	8	19.5
Insurance for person with DS <sup>a</sup>		
Private health insurance	7	17.1
Medicaid	15	36.6
Medicare	13	31.7
Military health care (TRICARE/VA/CHAMP)	1	2.4
Indian health service	1	2.4
Other	4	9.8

<sup>a</sup>More than one option available; as such, counts do not add up to total number of respondents.

### 3 | RESULTS

#### 3.1 | Demographics

Two focus groups in Spanish with a total of 7 Spanish-speaking caregivers and 20 in-depth interviews with PCPs were conducted. Of the 20 PCPs who participated in interviews, there were 17 who had a M.D. degree, two with a D.O., and one with a N.P. In this group, seven identified as Latino/a. An additional 41 parents/caregivers from a

variety of US states completed the online caregiver survey. Given the broad online recruitment efforts, a meaningful response rate could not be calculated for this convenience sample. See Table 1 for demographic breakdown. No completed paper surveys were received through the mail, in English or Spanish, prior to our analysis.

### 3.2 | Perspectives from PCPs: Providing care to patients with Down syndrome from primarily Spanish-speaking families

Language pervaded nearly every conversation across different themes and was considered to be one of the major barriers that primarily Spanish-speaking families face, impacting both mundane tasks from coordinating office visits with different specialists or wayfinding through a large hospital center, to more complicated tasks such as improving their health literacy through education. Distrust of important providers of auxiliary health services (e.g., Department of Developmental Services or food stamps) that are critical for the success of the individual with DS, and reluctance to sign up out of concern that doing so may threaten their privacy or citizenship status was cited as another barrier. Finally, the scarcity of quality and easily discoverable medical information translated into Spanish in modalities accessible to this population (e.g., mobile phone vs. desktop or laptop) emerged as a third critical barrier. Said one PCP: “Everyone has a phone, so you got to make it easy to navigate by phone so that you can kind of flip through it and get information and be able to kind of digest it...” These themes with reflective quotes are detailed in [Supplementary Materials Section 6](#).

PCPs shared that racial, ethnic, and language concordance between the families and providers may help to counter some barriers and facilitate the development of trust; looking the same, speaking the same language, coming from a shared culture matters. Said one PCP: “...I think that patient sees me and I'm brown-skinned and dark hair, and so I think that ... sameness kind of takes away that barrier. I'm not intimidating in any way.” Concordance is not limited to the PCP alone but extends to office staff and to other patient families. Said one PCP, “You see that maybe [other families] been able to—they've been willing to trust our program or how they're navigating the health system and create some agency.” Having an on-site interpreter readily available, while imperfect, can ease this process when PCPs do not speak Spanish. As well, recognizing that families may need assistance outside of what occurs during the office visit itself help making appointments with specialists, assisting with communication to schools about IEP plans, for example—may help shore up trust. These themes with reflective quotes are detailed in [Supplementary Materials Section 7](#).

### 3.3 | Perspective from caregivers: Healthcare experiences of people with Down syndrome where Spanish is the primary language spoken at home

In caregiver focus groups ([Supplementary Materials Section 8](#)), caregivers shared feelings of condescending, discriminatory treatment within the medical system and described how language barriers can

get in the way of their loved one receiving good care. Said one parent: “You often see it with doctors who are talking as if your level of education is very low. It does not happen with all. There are some professionals who are very respectful and very considerate, but not all of them are like that.” Parents also highlighted caregiver stress often exacerbated by social isolation. The latter may be due to the cultural stigma associated with the diagnosis or the lack of family support for those whose families remain in their home countries. Said one mother, “In my case, I kept the secret to myself. That did me a lot of harm, to us, to my daughter's father, and to me... Nobody wanted to tell the family...Because thinking that people could reject me.”

Ways in which trust could be facilitated was also discussed in these focus groups ([Supplementary Materials Section 9](#)). Caregivers shared that having knowledgeable, empathic providers is important, particularly those who are open to learning and sharing information. Caregivers noted the providers' role in helping parents gain confidence as they parent their child, and the importance of clinicians sharing their confidence in and hope for their loved one. Said one parent, “instead of encouraging me, [my pediatrician] made me feel afraid...So that made me feel intimidated, I felt bad. But now I have changed the clinic and moved to another place, and now I do have a new pediatrician, and I feel that he is very kind, very empathetic to say things, he has a lot of knowledge to express those things, and I feel more confident.” The importance of first conversations, especially those in which the diagnosis is shared, was specifically pointed out as an opportunity to set the stage. Said one parent, “[providers] should be more steeped in the topic. Because badly handled news affects mothers a lot. 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.” Another parent shared her experience this way: “Luckily, the pediatrician who attended me when [my daughter] was born...used to say to me: ‘Those children are a blast. You are going to see that for you it is going to be a blessing from God. You are going to thank God, every day, for having had it.’ Parents also expressed a strong preference for providers to focus on their loved one as an individual, rather than Down syndrome itself. Said one parent, “I don't know how to put it, but focus on the person, not on the diagnosis.”

In the online survey, of the 41 caregivers who responded, 29% feel that patients with Down syndrome who are Latino/a receive lower quality of medical care than most white patients with Down syndrome; 32% felt that patients with Down syndrome who do not speak English receive lower quality of medical care than most white patients with Down syndrome ([Supplementary Materials Section 10](#)).

In the multiple-choice format question, most respondents (71%) responded that they did not personally feel that their loved one with DS was treated unfairly or with disrespect ([Supplementary Materials Section 11](#)); a minority did feel that their loved one was treated unfairly or disrespectfully because of their race or ethnicity (12%) or because of their disability (10%). Respondents were less likely to feel disrespect because of their ability to pay for care or because of their religious or cultural beliefs.

About 59% were worried about taking time off from work to attend these tests and appointments and about 46% worried about the associated out-of-pocket expenses. Approximately, 54% of them worried to some extent that their loved one with Down syndrome will

be treated with respect when referred for a diagnostic test or appointment (Supplementary Materials Section 12), and about 37% of caregivers worried about themselves being treated with respect.

When it comes to patient-provider concordance (Supplementary Materials Section 13), slightly more caregivers reported that being of the same gender or same racial/ethnic background or having the same cultural/religious beliefs as their care provider was “not important at all” (44%, 41%, 49%, respectively) compared to those who felt these were “very important or somewhat important” (37%, 39%, 27%, respectively).

### 3.3.1 | In their own words: Role of race and ethnicity in experience of care, according to caregivers

On review of responses to the open-ended question in the caregiver survey (“How has race/ethnicity impacted the care of your loved one?”), 29 (of 41) respondents replied to this question.

Seventeen (59%) respondents reported that bias based on race and/or ethnicity pervades the care environment, with 12 (41%) reporting that they or their loved one with Down syndrome was personally impacted. Said one parent, “There is an assumption that I am less educated and when I ask questions about the line of treatment or don't agree, I am not taken seriously. I am talked to and my questions are answered as if I do not understand.” Two parents reported that they were treated with condescension and assumed it was because they were less educated. “It has influenced us in the sense that many health professionals assume that because you are from a Spanish-speaking country, typically poor countries with low education levels, they assume that we do not have higher education or we are unaware of everything related to Down syndrome on a medical level,” said one parent. Another parent experienced overt discrimination, “A doctor told us that everything was normal because my child had Down syndrome. On one occasion he said ‘oh, all of you Mexicans [think] that your child must be fat but he does not have to be thin, your child does not have weight problems. At another moment he made reference that all Mexicans believe that when my child has a lot of drool that his teeth come out. We had to change doctors.”

Of these 17 caregivers, 12 additionally commented on the impact language barriers have had in their experience of care. Six parents described how differences in language can make it difficult to establish a connection with their provider. Said one caregiver, “Race, language, culture form a barrier of prejudice on the part of doctors and nurses when providing the service. It shows, for example, in the greeting: most of the time it is not jovial. Therefore the ice does not break.” Four respondents shared how language barriers can make it difficult to access high quality care or services. Said one parent, “...More than anything because of communication and the definitive language barrier, it is more difficult to get services.” Two respondents shared that they felt that their care was rushed, also related to language barriers. Said one caregiver, “It's hard to attend to us quickly.”

The remaining 12 (41%) respondents felt that their loved ones with Down syndrome received good care with little to no personal or

environmental impact of race and ethnicity. Said one parent, “So far I have only seen good treatment with my 4 year old son who has Down syndrome. In all places, including hospitals, that I go to, I have been treated well.”

### 3.3.2 | Perspectives from caregivers: Accessing sources for health information

When it comes to searching for information about Down syndrome, of the 41 caregivers who responded to our online survey, about 51% felt at least somewhat confident that they could get information about Down syndrome if they needed it (Supplementary Materials Section 14). Even so, 32% of caregivers felt some degree of frustration and 27% reported that it took a lot of effort to find that information (Supplementary Materials Section 15). When asked about trusted messengers of healthcare information, they reported, in decreasing order of importance, doctors (78%), hospital/clinic web pages (46%), government health agencies (46%), charitable organizations (44%), Internet (24%), religious organizations/leaders (12%), and family/friends (7%) (Supplementary Materials Section 16).

Caregivers who participated in the focus groups discussed many of the same trusted messengers but noted the particular importance of peer support found through formal DS organizations and informally on social media and informational resources shared by local DS clinics and community organizations (Supplementary Materials Section 17).

## 4 | DISCUSSION

The results of this mixed methods study show that the healthcare of individuals with DS and their families does not escape the reality of bias and sometimes frank discrimination pervading the healthcare of Hispanic families with limited English proficiency in the United States across a broad range of conditions and interactions (Betancourt & Tan-McGrory, 2014; Calo et al., 2015; Eneriz-Wiemer et al., 2014). The participants in this study, informed by their lived experiences, reflected on their care experiences and offered constructive feedback on how barriers may be approached. Many of these points were similar to suggestions from Black/African American families, summarized by Krell et al. (2022), Spanish-speaking caregivers and the PCPs caring for their loved ones uniquely noted that: (1) language differences get in the way of giving and receiving good care and are ideally addressed with language concordant providers, but otherwise are best ameliorated by the availability of on-site interpreters who can be procured readily and then seamlessly integrated into the visit, (2) race and ethnic concordance can help to establish rapport and trust, and extends to other clinical and front office staff, and even to the other patients seen in the practice, (3) PCP offices ideally would be resourced and prepared to help navigate care beyond the visit and understand that Spanish-speaking families often have a distrust of providers, especially when one's legal citizenship or immigration status is felt to be at risk, and (4) providers should be empowered to craft more nuanced



schedules so that some patients who require more support (interpreter, or otherwise) can be offered more time.

Caregivers also emphasized that individual providers can: (1) understand that being knowledgeable about DS is important, but a provider's empathy, openness to learning—about DS, about their loved one, about their culture—and willingness to engage families as partners are just as highly valued, (2) focus on their loved one as a person, defined not by their syndrome or assumptions about their culture or their caregivers' level of education, and remember that first impressions begin with those first conversations regarding the diagnosis, which might take place even *before* their loved one is born, and (3) recognize and respect the burden and stress that comes with caregiving and for some, coincident social isolation.

Building mutual trust matters for the effective and equitable delivery of healthcare, but clinicians have a unique role to act as trusted messengers of health information and were identified as the most trusted among our survey respondents. Yet, PCPs report that they cannot do everything alone. In focus groups, caregivers emphasized the importance of their local nonprofit organizations for information-sharing and peer support creating an opportunity for the community to participate meaningfully. These diverse “people”-oriented conduits of trusted information suggest that more robust pathways to clinicians and community organizations are needed to ensure that Spanish-speaking families have access to the same health information, research opportunities and supportive technologies to which their English-proficient counterparts have easier access.

These pathways will take time to cultivate. The absence of responses to this group's multiple requests to 13 mainstream medical organizations to interview providers who identify as underrepresented minorities suggests that further exploration is needed to understand how to more efficiently and effectively connect with clinicians. In the meantime, those who are active and engaged today can continue to help families by developing the quality Spanish-language health information they need, the lack of which was cited by our PCPs as one of three key barriers to caring for this population. It may also be that resources exist but are not easily discoverable. How to make such resources easy to find is a significant challenge and deserves equal consideration. Families will almost certainly be asked to do more. Yet, our analysis showed that only about a third of survey respondents felt “completely” or “very” confident that they could find needed advice or information about DS and more than half felt “at least somewhat” frustrated during a recent search for information about DS. A path forward may include leveraging technologies to make quality information, resources, and opportunities easier to discover, while concurrently developing materials that help educate families about how to find and evaluate what they encounter.

The stakes could not be higher. While the Hispanic population comprises 18.7% of the US population (US Census Bureau, 2020), they represent anywhere from 5% to 11% (Cavazzoni et al., 2020; Rangel et al., 2018; UnidosUS, 2018) of those who are enrolled into clinical trials and other types of clinical research. With over 5% of the US population identifying as primarily Spanish-speakers, addressing

underrepresentation of individuals with limited English proficiency in clinical research is an essential step toward improving the diversity of participants. Without engaging those with limited English proficiency, many minorities underrepresented in research will remain so and, as a community, they will miss out on novel treatments—and, if they take a drug or use a device once it is approved in the course of “accepted” clinical care—they may experience a different level of or no benefit, or in some cases, unanticipated side effects. Furthermore, with the emergence of personalized and precision medicine, that is a direct byproduct of research, health inequities will surely grow.

## 5 | STUDY LIMITATIONS

This study's limitations are not insignificant. Our results are based on the thoughts and feedback of 41 survey respondents, 7 family caregivers, and 20 PCPs. Caregivers needed to be connected to the larger DS community through social media or membership in an advocacy organization. Survey respondents skewed toward higher levels of education. The survey itself was at approximately the 7th grade level and exclusively accessed online, which may have not been fully accessible to caregivers with lower literacy levels or technical skills. All had to feel comfortable enrolling for this project, sharing their identifying information, and doing so for the purpose of research. Given this selection bias and small sample, despite being recruited through all available mechanisms within the DS community, these results may not be generalizable to the broader DS community of Spanish-speaking families.

To capture the general healthcare experiences of primarily Spanish-speaking families in the survey, we relied on caregivers who self-identified as such and completed the survey in Spanish. We did not specifically ascertain their proficiency with English, which limits how nuanced our interpretation of the results can be as the experiences of those who are bilingual is likely to be different from those who are strictly monolingual. We also did not specifically ask for details about their PCP or the practices in which their dependents with DS are seen, including language fluency or availability of interpreters, which may influence, and potentially skew, how caregivers responded to some of the questions. Additionally, we did not assess the Spanish-language fluency of PCP participants, which might have allowed an opportunity to understand potential shifts in perspective between those who comfortably speak the language and those who do not.

Our results regarding the role of race and ethnicity in the care of individuals of DS tells only a small part of the story. A minority of caregivers surveyed reported that their care was personally affected by race or ethnicity in the multiple choice question section of the survey. However, significant barriers were reported by nearly half when survey respondents were given the opportunity to share their experiences in narrative form. Furthermore, race and discrimination emerged as one of three major themes in the caregiver focus group. These differences suggest that approaches to address barriers related

to race and ethnicity in DS care will require ongoing iterative exploration of the complicated and complicated-to-talk-about issues related to race and ethnicity using multiple modalities.

The key driver behind this inquiry was to identify barriers that prevented our engagement with minority populations in the DS community despite the team's established and long-standing relationship with the DS community and its national and local organizations. Through this research, we established that limited English proficiency is a major structural barrier in DS care in its own right, and we see that it conflates with and exacerbates underlying systemic racism, further compromising the trust that is fundamental to the provision of equitable healthcare. Future research should explore interventions to improve cultural competence and humility of trusted messengers, but not without the attendant development of resources those in the community—whether clinicians or organizers—need in order to engage with those who are not proficient in English. Finally, characterizing DSC2U's poor uptake in the Spanish-speaking community may reflect not a disparity in access to health information or research opportunity, but rather a disparity in appeal—that is, what are the perceptions of the use of technology for healthcare—and of research itself—in the Spanish-speaking DS community?

## 6 | CONCLUSION

Hispanic families of individuals with DS with limited English proficiency rely on the caregivers' effective advocacy for a loved one to gain access to oft-needed care, services across different facets of life, and scarce resources. Unlike more common health conditions, like diabetes or heart disease, a broader community comprising at least family, health providers, nonprofit groups, and others is essential to fully support the health of the patient with DS from a primarily Spanish speaking family. How to foster and strengthen such a network, enabling each to work in concert, deserves continued study.

### AUTHOR CONTRIBUTIONS

Jeanhee Chung: Conceptualization, methodology, investigation, writing—original draft. Kavita Krell: Conceptualization, methodology, software, validation, formal analysis, investigation, data curation, visualization, writing—original draft. Albert Pless, Jr.: Participant coordination, formal analysis, investigation, data curation, writing—original draft. Carie Michael: software, validation, formal analysis, investigation, resources, data curation, writing—original draft, writing—review and editing, visualization. Amy Torres: Conceptualization, methodology, software, validation, investigation, writing—review and editing, supervision, project administration. Sandra Baker: participant outreach, investigation. Jasmine M. Blake: participant outreach, investigation. Kelli Caughman: Participant outreach, investigation. Sarah Cullen: Participant outreach, investigation. Maureen Gallagher: Participant outreach, investigation. Roxanne Hoke-Chandler: Participant outreach, investigation. Julius Maina: Participant outreach, investigation. Diana McLuckie: Participant outreach and coordination. Kate O'Neill: Participant outreach. Angeles Peña: Participant outreach. Dina Royal: Participant outreach. Michelle Slape: Participant outreach.

Noemi Alice Spinazzi: Participant outreach, investigation, methodology. Carlos G. Torres: Methodology. Brian G. Skotko: Conceptualization, methodology, validation, formal analysis, investigation, resources, data curation, writing—original draft, writing—review and editing, visualization, funding acquisition. All authors have reviewed and agreed to the published version of the manuscript.

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### CONFLICT OF INTEREST STATEMENT

Dr. Skotko occasionally consults on the topic of Down syndrome through Gerson Lehrman Group. He receives remuneration from Down syndrome nonprofit organizations for speaking engagements and associated travel expenses. Dr. Skotko received annual royalties from Woodbine House, Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. Within the past 2 years, he has received research funding from F. Hoffmann-La Roche, Inc., AC Immune, and LuMind Research Down Syndrome Foundation to conduct clinical trials for people with Down syndrome. Dr. Skotko is occasionally asked to serve as an expert witness for legal cases where Down syndrome is discussed. Dr. Skotko serves in a nonpaid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. Dr. Skotko has a sister with Down syndrome.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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