Healthcare experiences and health information seeking practices of patients with Down syndrome from primarily Spanish-speaking households

SUPPLEMENTARY MATERIALS

Jeanhee Chung,[4] Kavita Krell,[1] Albert Pless, Jr.,[1] Carie Michael, SM,[2] Amy Torres,[1] Sandra Baker, Jasmine M. Blake, MD, MSPH,[3] Kelli Caughman, Sarah Cullen,[5] Maureen Gallagher,[5] Roxanne Hoke-Chandler, Julius Maina, Diana McLuckie, Kate O'Neill,[7] Angeles Peña, MD, MPH,[6] Dina Royal, MD, Michelle Slape,[7] Noemi Alice Spinazzi, MD,[8] Carlos G. Torres, MD,[9] Brian G. Skotko, MD, MPP[1,9]

1. Down Syndrome Program, Division of Medical Genetics and Metabolism, Department of Pediatrics, Massachusetts General Hospital, Boston, MA
2. Mongan Institute, Massachusetts General Hospital, Boston, MA
3. Departments of Internal Medicine and Pediatrics, Icahn School of Medicine at Mount Sinai, New York, NY
4. Laboratory of Computer Science, Department of Medicine, Massachusetts General Hospital, Boston, MA
5. Massachusetts Down Syndrome Congress, Burlington, MA
6. Department of Pediatrics, Oregon Health & Science University, Portland, OR
7. LuMind IDSC Down Syndrome Foundation, Burlington, MA
8. Division of Primary Care, Department of Pediatrics, University of California San Francisco Benioff Children's Hospital Oakland, Oakland, CA
9. Department of Pediatrics, Harvard Medical School, Boston, MA

Table of Contents

1. Caregiver Survey (English-, print-version)

CAREGIVER SURVEY

PART A: ELIGIBILITY

1. Are you the parent or caregiver of a person with Down syndrome?

☐ Yes
☐ No ⇨ If NO, thank you for your interest in our survey.

2. Is your loved one with Down syndrome Black, African American, of African descent, or mixed race AND/OR is Spanish the PRIMARY language spoken in your home?

☐ Yes
☐ No ⇨ If NO, thank you for your interest in our survey.

PART B: EXPERIENCE OF CARE

3. For each of the following groups of patients with Down syndrome, do you think most receive a <u>higher quality</u> of medical care, <u>same quality</u> of medical care, or <u>lower quality</u> of medical care than most *White* patients with Down syndrome?

SELECT ONE PER ROW

	Higher quality of medical care	**Same quality of medical care**	**Lower quality of medical care**	**Don't know**
a) Black or African American patients with Down syndrome…	☐	☐	☐	☐
b) Hispanic or Latino patients with Down syndrome…	☐	☐	☐	☐
c) Asian or Asian-American patients with Down syndrome	☐	☐	☐	☐
d) Patients with Down syndrome who cannot speak English receive…?	☐	☐	☐	☐

4. Please think about all of the experiences you have had with health care visits in the LAST YEAR. Have you personally ever felt that doctors, nurses, or other hospital staff treated your loved one with Down syndrome unfairly or with disrespect because…

SELECT ONE PER ROW

	Yes	**No**	**Don't Know**
a) Of your loved one's disability?	☐	☐	☐
b) Of your loved one's racial or ethnic background?	☐	☐	☐
c) Of your loved one's religion or religious beliefs?	☐	☐	☐
d) You were not able to pay for your care or did not have insurance?	☐	☐	☐

5. **When your loved one with Down syndrome has been referred for a diagnostic test or appointment, have you worried about any of the following?**

SELECT ONE PER ROW

	Yes	**Yes, somewhat**	**No**
a. What it will cost you out of your pocket?	☐	☐	☐
b. Getting transportation to appointments?	☐	☐	☐
c. Getting time off from work or other responsibilities to keep the appointment?	☐	☐	☐
d. That you will be treated with respect by doctors and nurses?	☐	☐	☐
e. That your loved one will be treated with respect?	☐	☐	☐

6. **In general, how important is it to you to have <u>your loved one</u> be cared for by**

SELECT ONE PER ROW

	Very important	**Somewhat important**	**Not important at all**	**No answer**
a) Doctors and nurses who are the same gender (male, female) as your loved one?	☐	☐	☐	☐
b) Doctors and nurses with the same racial/ethnic background as you?	☐	☐	☐	☐
c) Doctors and nurses who share your cultural/religious beliefs?	☐	☐	☐	☐

7. **How has race and/or ethnicity impacted the care for your loved one with Down syndrome?**

PART C: LOOKING FOR HEALTH INFORMATION

8. Have you ever looked for information about Down syndrome from any source?

☐ Yes
☐ No ⇨ Go to question 10.

9. Based on the results of your most recent search for information about Down syndrome, how much do you agree or disagree with each of the following statements?

SELECT ONE PER ROW

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
a) It took a lot of effort to get the information you needed	☐	☐	☐	☐
b) You felt frustrated during your search for the information	☐	☐	☐	☐

10. Overall, how confident are you that you could get advice or information about Down syndrome if you needed it?

☐ Completely confident
☐ Very confident
☐ Somewhat confident
☐ A little confident
☐ Not confident at all

11. In general, how much would you trust information about Down syndrome from each of the following?

SELECT ONE PER ROW

	Not at all	A little	Some	A lot
a) A doctor	☐	☐	☐	☐
b) Family or friends	☐	☐	☐	☐
c) Government health agencies	☐	☐	☐	☐
d) Charitable organizations	☐	☐	☐	☐
e) Religious organizations and leaders	☐	☐	☐	☐
f) Hospital or clinic webpage	☐	☐	☐	☐
g) the internet	☐	☐	☐	☐

12. What are your favorite <u>online</u> sources for information on Down syndrome?

PART C: COVID EXPERIENCE

13. In the past year, has the COVID-19 pandemic had a *very serious*, *somewhat serious,* or *not serious* impact on… (check one box on each row)

	Very serious	Somewhat serious	Not serious
a) Your work or employment	☐	☐	☐
b) Your feelings of anxiety or depression	☐	☐	☐
c) Access to health care services when your loved one with Down syndrome needed them	☐	☐	☐
d) Access to mental health services when your loved one with Down syndrome needed them	☐	☐	☐
e) Your loved one with Down syndrome's contact with family or close friends	☐	☐	☐
f) The overall health of your loved one with Down syndrome	☐	☐	☐

PART D: ABOUT YOU

14. What type of health insurance or health coverage does your loved one currently have?
Check all that apply

- ☐ Private health insurance
- ☐ Medicare
- ☐ Medicaid
- ☐ Military health care (TRICARE/VA/CHAMP)
- ☐ Indian Health Service
- ☐ No insurance coverage of any kind
- ☐ Other, please specify
  ____

15. How are you related to your loved one with Down syndrome?

- ☐ Mother or step-mother
- ☐ Father or step-father
- ☐ Grandparent
- ☐ Aunt or Uncle
- ☐ Sibling, half-sibling, or step-sibling
- ☐ Other

16. Are you?

- ☐ Male
- ☐ Female
- ☐ Non-binary or other
- ☐ Prefer not to answer

☐

17. Are you Hispanic, Latino/a, or of Spanish Origin? (check one)

- ☐ Yes
- ☐ No

18. Do you consider yourself to be…?
(One or more categories may be selected)

- ☐ Black or African American
- ☐ Asian
- ☐ Native American or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White
- ☐ More than one race
- ☐ Other (please specify) ___________

19. What is the last grade that you completed in school? (check one)

- ☐ Less than high school
- ☐ High school graduate (grade 12 or GED)
- ☐ Some college or technical/vocational school
- ☐ College graduate (B.S., B.A.)
- ☐ More than college

20. **What is your home zip code?**

☐☐☐☐☐

Thank you for participating in this survey!

2. Caregiver Survey (Spanish-, print-version)

ENCUESTA PARA CUIDADORES

PARTE A: ELEGIBILIDAD

1. ¿El español es el PRINCIPAL idioma que se habla en su hogar?

☐ **Sí**
☐ **No** ⇨ Si la respuesta es NO, gracias por su interés en nuestra encuesta.

2. ¿Es usted padre, madre o cuidador de una persona con síndrome de Down?

☐ Sí
☐ No ⇨ Si la respuesta es NO, gracias por su interés en nuestra encuesta.

PARTE B: EXPERIENCIA DE ATENCIÓN

3. Para cada uno de los siguientes grupos de pacientes con síndrome de Down, ¿considera usted que la mayor parte de ellos recibe una atención médica de <u>mejor calidad</u>, de <u>igual calidad</u> o de <u>menor calidad</u> que la mayoría de los pacientes *blancos* con síndrome de Down?

SELECCIONE UNA OPCIÓN POR FILA

	Atención médica de mejor calidad	**Atención médica de igual calidad**	**Atención médica de menor calidad**	**No sé**
a) Pacientes negros o afroamericanos con síndrome de Down	☐	☐	☐	☐
b) Pacientes hispanos o latinos con síndrome de Down	☐	☐	☐	☐
c) Pacientes asiáticos o asiáticos americanos con síndrome de Down	☐	☐	☐	☐
d) Pacientes con síndrome de Down que no hablan inglés	☐	☐	☐	☐

4. Por favor, piense en todas las experiencias que ha tenido durante las visitas de atención médica en el ÚLTIMO AÑO. ¿Alguna vez sintió personalmente que los médicos, los enfermeros u otro personal del hospital trataron a su ser querido con síndrome de Down de forma injusta o irrespetuosa debido a…

SELECCIONE UNA OPCIÓN POR

	Sí	**No**	**No sé**
a) la discapacidad de su ser querido?	☐	☐	☐
b) los orígenes étnicos o raciales de su ser querido?	☐	☐	☐
c) la religión o las creencias religiosas de su ser querido?	☐	☐	☐
d) que no podía pagar su atención médica o no tenía seguro?	☐	☐	☐

5. **Cuando su ser querido con síndrome de Down fue remitido para pruebas diagnósticas o consultas, ¿usted se preocupó por alguno de los siguientes aspectos?**

SELECCIONE UNA OPCIÓN POR FILA

	Sí	**Sí, un poco**	**No**
a. ¿Cuánto tendría que pagar de su bolsillo?	☐	☐	☐
b. ¿Conseguir transporte para llegar a las consultas?	☐	☐	☐
c. ¿Ausentarse del trabajo o de otras responsabilidades para poder asistir a la consulta?	☐	☐	☐
d. ¿Que los médicos y enfermeros lo traten con respeto?	☐	☐	☐
e. ¿Que traten con respeto a su ser querido?	☐	☐	☐

6. **En general, ¿cuán importante es para usted que <u>su ser querido</u> reciba atención por parte de**

SELECCIONE UNA OPCIÓN POR FILA

	Muy importante	**Algo importante**	**Para nada importante**	**Sin respuesta**
a) médicos y enfermeros del mismo género (masculino, femenino) que su ser querido con síndrome de Down?	☐	☐	☐	☐
b) médicos y enfermeros del mismo origen racial/étnico que su ser querido con síndrome de Down?	☐	☐	☐	☐
c) médicos y enfermeros que compartan sus creencias culturales/religiosas?	☐	☐	☐	☐

7. **¿Cómo ha influido su raza y/o etnia en la atención que recibe su ser querido con síndrome de Down?**

PARTE C: BÚSQUEDA DE INFORMACIÓN DE SALUD

8. ¿Alguna vez ha buscado información sobre el síndrome de Down en cualquier fuente?

☐ Sí
☐ No ⇨ Si la respuesta es NO, diríjase a la pregunta N.° 11.

10. Según los resultados de su búsqueda de información sobre síndrome de Down más reciente, ¿cuán de acuerdo o en desacuerdo está con cada una de las siguientes afirmaciones?

SELECCIONE UNA OPCIÓN POR FILA

	Totalmente en desacuerdo	**Un poco en desacuerd**	**Un poco de acuerdo**	**Totalmente de acuerdo**
a) Le requirió mucho esfuerzo conseguir la información que necesitaba	☐	☐	☐	☐
b) Se sintió frustrado/a durante la búsqueda de información	☐	☐	☐	☐

11. En términos generales, ¿cuán seguro/a se siente de poder obtener asesoramiento o información sobre el síndrome de Down en caso de necesidad?

☐ Completamente seguro/a
☐ Muy seguro/a
☐ Bastante seguro/a
☐ Un poco seguro/a
☐ Para nada seguro/a

12. En general, ¿en qué medida confiaría en la información sobre síndrome de Down proporcionada por cada una de las siguientes fuentes?

SELECCIONE UNA OPCIÓN POR FILA

	Para nada	**Un poco**	**Bastante**	**Mucho**
a) Un médico	☐	☐	☐	☐
b) Un familiar o amigo	☐	☐	☐	☐
c) Agencias de salud gubernamentales	☐	☐	☐	☐
d) Organizaciones benéficas	☐	☐	☐	☐
e) Organizaciones y autoridades religiosas	☐	☐	☐	☐
f) Página web del hospital o la clínica	☐	☐	☐	☐
g) Internet	☐	☐	☐	☐

13. ¿Cuáles son sus fuentes favoritas de información <u>en línea</u> sobre síndrome de Down?

PARTE D: EXPERIENCIA FRENTE AL COVID

14. En el último año, la pandemia de COVID-19 ha tenido un impacto *muy grave*, *algo grave* o *para nada grave* en… (marque un casillero en cada fila)

	Muy grave	**Algo grave**	**Para nada grave**
a) su trabajo o empleo	☐	☐	☐
b) sus sentimientos de ansiedad o depresión	☐	☐	☐
c) el acceso a servicios de atención médica cuando su ser querido con síndrome de Down los necesitaba	☐	☐	☐
d) el acceso a servicios de atención mental cuando su ser querido con síndrome de Down los necesitaba	☐	☐	☐
e) el contacto de su ser querido con síndrome de Down con familiares o amigos cercanos	☐	☐	☐
f) el estado general de salud de su ser querido con síndrome de Down	☐	☐	☐

PARTE E: ACERCA DE USTED

15. ¿Qué tipo de seguro o cobertura de salud tiene actualmente su ser querido? *Marque todas las opciones que correspondan*

☐ Seguro de salud privado
☐ Medicare
☐ Medicaid
☐ Sistema de atención de salud militar (TRICARE/VA/CHAMP)
☐ Indian Health Service
☐ No cuenta con cobertura de seguro de ningún tipo
☐ Otro, por favor, especifique
____

16. ¿Qué relación tiene con su ser querido con síndrome de Down?

☐ Madre o madrastra
☐ Padre o padrastro
☐ Abuelo o abuela
☐ Tía o tío
☐ Hermano/a, medio hermano/a o hermanastro/a
☐ Otra

17. ¿Cuál es su género?

☐ Masculino
☐ Femenino
☐
☐ No binario u otro
☐ Prefiero no responder

18. ¿Es usted hispano/a, latino/a o de origen español? (marque una opción)

☐ Sí
☐ No

19. ¿Usted se considera…?
(Puede seleccionar una o más categorías)

☐ Negro/a o afroamericano/a
☐ Asiático/a
☐ Nativo/a americano/a o nativo/a de Alaska
☐ Nativo/a de Hawái o de otra isla del Pacífico
☐ Blanco/a
☐ De más de una raza
☐ Otra (por favor, especifique) ___________

20. ¿Cuál es el nivel de estudios más alto que alcanzó? (marque una opción)

☐ Escuela secundaria incompleta
☐ Escuela secundaria completa (12.° grado o GED)
☐ Estudios universitarios o técnicos/profesionales incompletos
☐ Estudios universitarios completos (B.S., B.A.)
☐ Estudios de posgrado

21. ¿Cuál es el código postal de su hogar?

☐ ☐ ☐ ☐ ☐

¡Gracias por participar en esta encuesta!

3. Caregiver Focus Group: Spanish language social media recruitment advertisements

Facebook/LinkedIn
Nuestro programa busca cuidadores de personas con síndrome de Down que hablen español como idioma principal para participar en un grupo de discusión virtual (Zoom). Queremos comprender mejor las barreras y los facilitadores que enfrentan las personas con síndrome de Down de estas comunidades para acceder a la atención médica. Todos los cuidadores recibirán una tarjeta de regalo de Amazon de $50 por su participación en esta discusión de una hora. Si tiene interés, póngase en contacto con dsc2u@mgh.harvard.edu.

Twitter
Nuestro programa busca cuidadores de personas con síndrome de Down que hablen español como idioma principal para participar en un grupo de discusión virtual. Haga clic en el enlace para obtener más información sobre el proyecto. (link)

4. Caregiver Focus Group: Screening survey for caregivers identified online

Diversity Project Interest Survey

Please complete the survey below.

Thank you!

Are you fluent in written and spoken English?	○ Yes ○ No
Are you fluent in written and spoken Spanish?	○ Yes ○ No
Are you over the age of 18 years?	○ Yes ○ No
Are you a primary caregiver of an individual with Down syndrome?	○ Yes ○ No
Do you live in the United States?	○ Yes ○ No
What is the age of your loved one with Down syndrome?	______________________
Which of the following best describes your loved one with Down syndrome's race (select any that apply)?	☐ White or Caucasian ☐ Black or African-American ☐ Asian or Pacific Islander ☐ Native American or Alaskan Native ☐ Other
If other, please describe:	______________________
Which of the following best describes your loved one with Down syndrome's ethnicity?	○ Hispanic or Latino ○ Not Hispanic or Latino
What is the age of the individual with Down syndrome?	______________________
What is the gender of the individual with Down syndrome?	○ Male ○ Female ○ Other
How are you related to your loved one with Down syndrome?	☐ Mother or father ☐ Grandparent ☐ Aunt or Uncle ☐ Brother or sister ☐ Other relative ☐ Legal guardian ☐ Someone else
Which statement applies to your living situation?	☐ My loved one who has Down syndrome lives with me ☐ My loved one who has Down syndrome does NOT live with me

How did you learn about this focus group study (choose any that apply)?	☐ Social Media ☐ Email ☐ Online posting ☐ Website ☐ Someone told me about it ☐ Other
Are you able to participate on Zoom with video or dial in?	○ With video ○ Dial in only
What type of health insurance or health coverage does your loved one currently have? Check all that apply	○ Private health insurance ○ Medicare ○ Medicaid ○ Military health care (TRICARE/VA/CHAMP-VA) ○ Indian Health Service ○ No insurance coverage of any kind ○ Other
If other, please state your primary insurance:	
What are your favorite sources for information on Down syndrome?	

Thank you for your interest in the focus group research project. Please provide your contact information, and let us know the best method to contact you in the subsequent questions.

You will then be contacted by our research team to schedule a time for the focus group. If you have questions, you can email the Principal Investigator, Dr. Brian Skotko at dsc2u@mgh.harvard.edu.

First Name:	
Last Name:	
Please list your email address:	
Please list your phone number with area code:	
The Massachusetts General Hospital Down Syndrome Program has ongoing research projects. MGH Down Syndrome Program Research Webpage Would you like to be contacted about other research projects?	○ Yes ○ No

5. Caregiver Survey: Spanish language social media recruitment advertisements

DS Connect

Social Media

¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Complete la encuesta para ayudarnos a comprender mejor las barreras que su ser querido tiene para acceder a la atención médica.
https://redcap.link/gq5v0nmk

LuMind IDSC

Facebook/Instagram

¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Considere completar esta encuesta para ayudarnos a comprender mejor las barreras y los facilitadores que su ser querido tiene para acceder a la atención médica. https://redcap.link/cpxygqqo

Twitter

¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Complete la encuesta para ayudarnos a comprender mejor las barreras que su ser querido tiene para acceder a la atención médica.
https://redcap.link/cpxygqqo

MDSC

Facebook/Instagram

¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Considere completar esta encuesta para ayudarnos a comprender mejor las barreras y los facilitadores que su ser querido tiene para acceder a la atención médica. https://redcap.link/wuh6b429

Twitter

¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Complete la encuesta para ayudarnos a comprender mejor las barreras que su ser querido tiene para acceder a la atención médica.
https://redcap.link/wuh6b429

MGH Down Syndrome Program, Dr. Brian Skotko, PCP Working Groups, and Caregiver Working Groups and DSMIG

Facebook/Instagram
¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Considere completar esta encuesta para ayudarnos a comprender mejor las barreras y los facilitadores que su ser querido tiene para acceder a la atención médica. https://redcap.link/k6gm59qo

Twitter
¿Es el cuidador de un ser querido con síndrome de Down en los EE.UU. que habla principalmente español? Complete la encuesta para ayudarnos a comprender mejor las barreras que su ser querido tiene para acceder a la atención médica.
https://redcap.link/68vptj1p

6. PCP Interviews: Barriers for Spanish-speaking patients and families

Language a Barrier to Resources beyond PCP office (spoken language)	“And then a lot of my Spanish-speaking recent immigrant families, all have the same issues. And then additionally, when the subspecialist'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. So a lot of it— especially during the pandemic, a lot of stuff that's been on Zoom, they just haven't done at all. So I think time, money, transportation, child care of other kids are all major barriers. Language is obviously a major barrier in terms of just coordination and communication. And then equality with technology and scheduling…” “So I think that the language, the literacy part of that, transportation, just because I practice about 30 miles north of Seattle, so they have to drive down to Seattle. And the Children's Hospital is like a maze. I mean, you easily can get lost. So I think it's a bit overwhelming at the beginning until they kind of get the hang of it and start seeing the specialists and whatnot. So I think transportation can sometimes be a barrier. Cost, not so much because a lot of my Hispanic families are plugged in with like state aid, so that doesn't tend to be an issue...Yeah, The biggest one for me. I think is the language. I think that's the hardest part for families.”
Distrust of Service Providers	“There's a lot of distrust with DDS [Disability Determination Services] though, I think maybe that is some of the relationship of having people who either immigration status or not understanding, I think there are some people who are afraid of DDS.” “I think trust comes more and I have a 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, and definitely, people coming into the home makes them really anxious in government programs like D.D.S. makes them anxious. They usually are pretty okay with internet if they don't have to put in a lot of personal stuff, but if they have to put in a lot of personal stuff, they might get anxious.”
Patient Education Materials and Websites	“My patients, it's primarily Spanish, even information, pamphlets in Spanish, websites in Spanish. But then also with that, in a language that they're able to [understand]. And then also thinking of just kind of from a different angle in formats that are accessible on their cell phone because some of these sites are very specific and they don't transfer. The way they look, they look really appealing on the screen, but not everyone has a laptop. 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...good for a short attention span, being able to plug things that kind of see them relatively quickly, and then just being able to make it visually appealing. Because if it's just a lot of text, no one's going to read that.”

“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, finding appropriately translated information, right, because that's the other big part too. I can say, ‘Oh yeah, check out whatever website. The AAP has a great thing on Down syndrome,’ but if they're Spanish speakers…”

7. PCP Interviews: Facilitators of trust for Spanish-speaking patients and families

Racial, Ethnic, and Language Concordance	“I think just being very welcoming, especially on their first appointment, making sure they know how to reach you, and giving them lots of different ways to reach you. So a lot of my families don't understand how to use the electronic medical record portal, go to MyChart, and especially with Spanish. So I have a lot of families who have my phone number, and they have my email address that's not through that system. So they contact me that way, and then I call them back. So I think figuring out for each family how would best communicate with you. They may not have a computer. They may not have a cell phone that's active.” *(Spanish-speaking, Hispanic PCP)*
	“So I think what's helpful is patience. And then I think having providers and health personnel that are of the same background, cultural background, is really helpful. I don't take any offense of it. I think it's just— there's more trust if it comes from somebody who's a native Spanish speaker or somebody who's African-American. You feel you feel more heard. And so we try to accommodate that in our clinic, not with providers...when we have in-person interpreters, we have really good in-person interpreters.”
	“Yes, I think absolutely being able to speak the language is so important and not having and not—I guess, because I'm fortunate because I speak two languages, I don't need an interpreter. And so I think that just makes the visit go so much smoother because I'm not constantly being interrupted. And I think that patient sees me and I'm brown-skinned and dark hair, and so I think that other part of that. I think kind of that sameness kind of takes away that barrier. I'm not intimidating in any way.”
	“I'm a native Spanish speaker because my mom is from Peru and my dad's from Spain, I think that definitely helps build trust with me. I also have a team that's very much working hard to make sure that the materials that we give to families are written in Spanish and so that part helps them build more trust with my nursing staff.”
	“Being able to explain things in their language, in a way that they understand: I think it's one of the most helpful things. And hearing it from someone that they would consider part of their culture, understands their background, makes an incredible difference. Because you'll have that kind of Eureka moment when they're like, ‘I didn't know that. I was never explained that. No one explained this part of my entitlements.’ Or that we're entitled to something like an IEP.”
	“But also, the other thing we do is—pre-COVID, it's very hard to do now—is we try to have a organic parent community. And if you can get parents to meet with each other, even though the diagnosis might be different, I think that's the best way to to create trust is you see other families. You see that maybe they they've been able to—they've been willing to trust our program or how they're navigating the health system and create some agency.”
Use of an In-Person Interpreter	“Just being there and making sure if I need to use an interpreter or if there's something complex, I look ahead in my schedule and give them more time in the visit. I think it's just really important to ask open-ended questions and listen.”

	"I mean, first of all, when there's interpreter, that's just a third party in there. So it's just one more person kind of knowing your personal stuff. So that's makes it less intimate. And then just her being able to just speak freely and not have to kind of translate in her own brain, speaking a second language for herself, I'm sure was a better feel". "We have a Spanish interpreter in person. They come, and they'll be available on the floor, and it's just so much better than having somebody online. We usually would have interpreters on the phone, and then the signal gets lost, or I'll hear them and, me knowing Spanish, I know that they cut out some of the words. And I'm wondering if that's because of the phone or because of the kind of speed of things on the phone versus in person. And it's always so much more flawless when we have an interpreter in person, and so I appreciate that."
Help Navigate Care Beyond the PCP Office	"I think sometimes they may have difficulties with scheduling appointments and so we try to work around that by scheduling them for them because sometimes when they are speaking to someone on the phone, I think they may be difficult to understand and they might not fully understand what's being told to them and so that— because the registration or scheduling staff may not be using an interpreter." "Because there's so many pieces that can be missed. And the kid really needs to have perfect eyes laid on them and have a perfect understanding between the caregiver and the provider. And so I think that's a huge thing that needs to be communicated across all providers. That they need to make sure that not only the medical literacy is up to par for the parent, but also in general, that just language barriers is something that is so easy to knock down and people just easily overlook it." "Well, so start with language, certainly, it's a barrier. It's a barrier for getting appointments. They have multiples of specialists often that they need to see. They have labs they have to get. They have just all the navigation of the health system. And in California, we're pretty lucky because we have people who speak Spanish or we have interpreters. But—I notice for my Spanish speaking families, the parents are always a little bit intimidated to even call if they don't know that there's a Spanish speaking option, or just navigating the voicemail system. All of that is just an automatic barrier. I think it's a huge barrier for the school district, especially in COVID. For all my kids, regardless of Down syndrome and special ed, their services have not been what they should be or what they were pre-COVID. And so then the parents are having a really hard time getting a hold of the different teachers, the principal, or the school, especially with the language barrier. So that impacts the patients with Down syndrome getting their IEP and getting the things that they need. It impacts them being able to talk to the teacher directly if they don't speak Spanish. So I think that that piece of the language barrier it's huge, right? It's also a problem for them getting food for their families, all the basic needs met."

8. Caregiver Focus Group: Barriers and experiences of disrespect/discrimination

Language differences getting in the way	"But even I, who speaks English, sometimes feel lost, But I also say, people who do not speak English do not know, there are many things that do not know what happens to them...It's very sad, because...we all deserve more, no matter what color your skin is, whether you speak English or not. All our children and all those with different disabilities deserve the best." "Generally there are the moms, the moms who participate, the moms who investigate, the moms who join groups are the moms who, in some way, defend themselves with the language. And those that do not, which are many, are left behind; they run out of the information they need to help their children thrive. In the area of autism and Down syndrome there is so much lack of information...So, there are still a lot of disadvantages for our mothers because they do not have knowledge or are not armed with the necessary knowledge to be able to identify if the son or daughter needs the diagnosis." "When she was born, we did not have access to, for example, Medicaid, because here in Texas everything is based on income, all expenses had to be paid by us. And, as I told you, the waivers or services took six years. Fortunately, I put her on the list when she was almost two years old, last year they spoke to us and they already gave us one of the waivers and, thanks to that, she was able to receive what is called Medicaid. But it took eight years for her...So, that's the way it happens with many Hispanic families, who don't know what there is." "And I think that then more information in Spanish, above all, because sometimes one finds a lot of information in English, but sometimes it gets lost in the translation, or one does not know how to explain to other mothers who do not speak English. I had the case of a mother...Her baby also had to stay in the hospital...they couldn't explain to her, the interpreters themselves couldn't explain well what was what was happening. And I think that what you say affects you much more like mom, not knowing and not being able to explain to you in your own language what is happening."
Social isolation and caregiver stress	"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. 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 could reject me. People could say something that would offend me. So we didn't want to say any of that." "I understand that it is important for the child to integrate...I've lived here in the United States for ten years. I had my first son in my country—I am a Dominican—my son, the oldest, came when he was five years old. And when I had [my son with Down syndrome], my [other] son was 13 years old, and I compare. Motherhood in itself is alone, it is very lonely in this country, because one does not have their families: my mother lives in my country, my father; I have a sister who lives here, but my other sister lives there; my friends, my mother-in-law, everyone lives in my country...motherhood in itself is hard, because it is lonely, lonely, that is, your friends who do not have children or have children of other ages, each one takes their own, add to that a diagnosis."

Condescending, discriminatory treatment	“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.”
	“I think it is the first time that I have taken [my son with Down syndrome] to a hematologist. I consulted the doctor about [his] markers, who have come a little altered over time, so I felt the doctor's concern, and the doctor told me: "You're right." But if I don't tell him, he just ignores that and assumes all of the tests have come back normal.”
	“From the first moment, [my son] was discriminated against, not only because of his disability, but because he was a Hispanic boy. So, that was a shock that took [my son] back, he regressed considerably after he was coming along so well...But I have lived it and there are and some my family friends have lived it, the discrimination is double, it is double because of disability and because of your race.”
	“I also believe that we as parents should do our part. At the same time, if we do not feel comfortable with the pediatrician or we feel that he is not taking us seriously, look elsewhere.”
	“In other words, there are many who assume...that because she has Down syndrome, she is going to have Xs or something like that. It happened to me that I had to change my pediatrician. I didn't have to change, because she dumped me. Literally told me: ‘I can't receive you anymore.’ Why? Because I was going with a lot of information that I was interested in her reading, getting informed or helping me with that information, for me to understand and that in fact we could discuss something with which she did not agree or that I understood that it had to be one way. And she literally told me: ‘I can't take you anymore.’ Meaning, she preferred not to see my daughter anymore instead of doing a bit more reading and understand her a little better.”

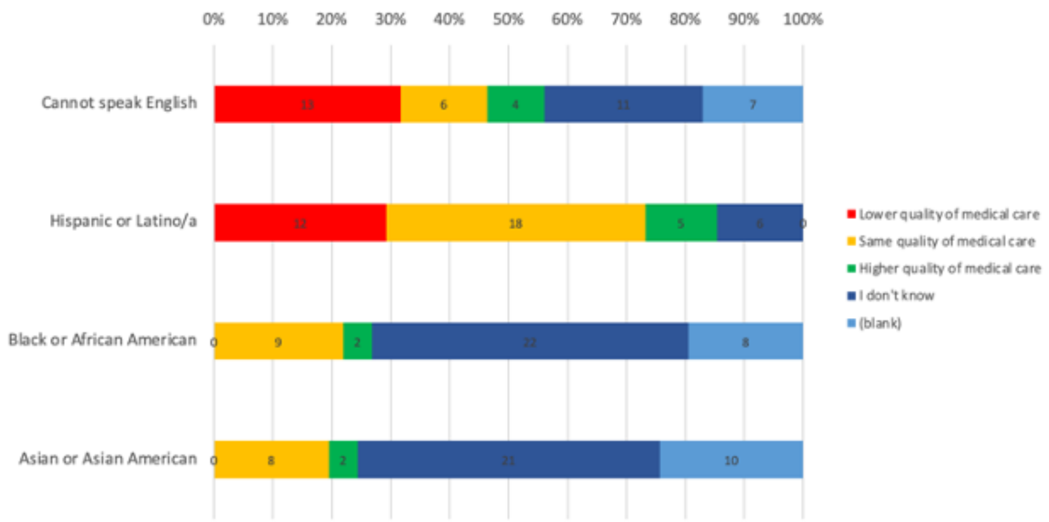
9. Caregiver Focus Group: Facilitators of trust in providers and the medical system

Focus on patient, not only Down syndrome diagnosis	“Whenever you are going to deal with a family of a child with Down syndrome, do it as if it were your own child, just as you would like to be cared for, with the same sensitivity that they can treat their children and their family.” “I don't know how to put it, but focus on the person, not on the diagnosis.” “So, that for me would be very important, that the doctors did not assume that because she has Down syndrome that is how it is or that is going to be, or not anymore.”
Knowledgeable, empathetic providers	“The pediatrician now, where I go, is not a pediatrician, but is a nurse practitioner. My experience has been incredible because I have realized that nurse practitioners are much better, at the level of what they want to learn, that they are more interested, than even at the level of experience - I imagine that as they are the ones who are really with people when they have a problem. They know a lot, they are very interested in learning, and yes, they tell me: "Send me everything you want by mail, I will read it. If you have any new information that you are interested in letting me know." She is wonderful, I am happy with her, much better than the pediatrician, really.” “When I first went to the pediatrician...I felt bad because he began to tell me that children with Down syndrome handled a lot with fever, that you had to be very careful, that you had to always be with them. I mean, instead of encouraging me, he 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.” “That the doctors and nurses who at that time are with a family that have a baby with this condition, that they be more empathetic, more professional to say things, even though one does not speak the language, that they try to— because for that there is an interpreter there, so that one does not feel bad, because one can be shocked.” “Empathy is the word that most—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 towards our daughters.” “Not only the doctor, but all the staff of the offices, if they could know, have more knowledge of this, it would be very good, it would be informative, to know the other side of the coin. Precisely helping them to know what to say, what not to say, what things can be received in a better way. Knowing that, I think it would be very important, because I realize that not everyone often knows how to say things. A lot of times it's from a lack of— not just intention, but a lack of knowledge, of how to say certain things.”
First conversations about Down syndrome	“Yes, in relation to the doctors, really, they are the ones who give you the news, they give you the diagnosis. Yes, they 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.”

“Luckily, the pediatrician who attended me when she was born, she simply told me: ‘I know that you are very worried about the girl, but the condition is the least compared to whether it brings a medical problem.’ So, she told me: ‘We are going to review it completely and ask God not to bring any kind of problems, because the condition, that–’, for her the condition did not have any type of concern. She 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.’”

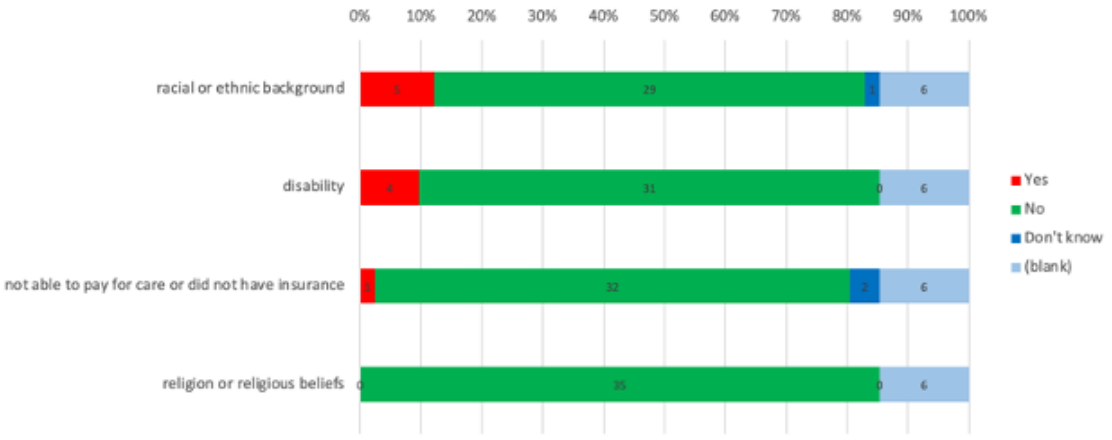
“At first, since my baby was in intensive care, there they give you a lot of information, but it was something that I did not understand very well. But then I had to come home and my baby stayed in the hospital, and I didn't really understand the syndrome. And then, time passed and they gave me my daughter and I started looking for information on YouTube, and I began to realize that it was not that difficult, that the families started out like they didn't understand, but then they kind of are a very happy cast. So that's what I found on YouTube, that's why I got information from families that already have children with the syndrome. So that is how I have become familiar, through the information on YouTube. And I always keep trying to search there.”

10. Quality of medical care



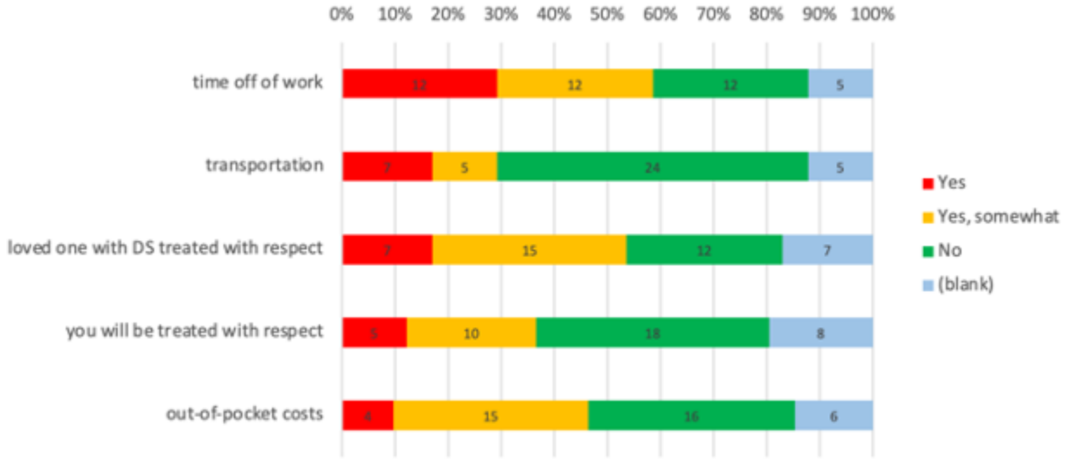
Supplement 10. “For each of the following groups of patients with Down syndrome, do you think most receive a higher quality of medical care, same quality of medical care, or lower quality of medical care than most white patients with Down syndrome?” N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

11. Experiences with health care visits



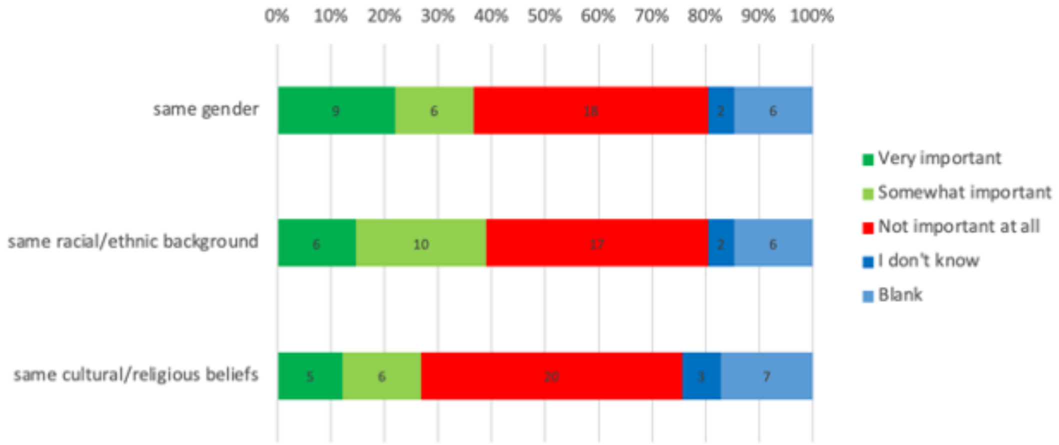
Supplement 11. “Please think about all of the experiences you have had with health care visits in the LAST YEAR. Have you personally felt that doctors, nurses, or other hospital staff treated your loved one with Down syndrome unfairly or with disrespect because…” N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

12. Worries related to referrals for diagnostic tests or appointments



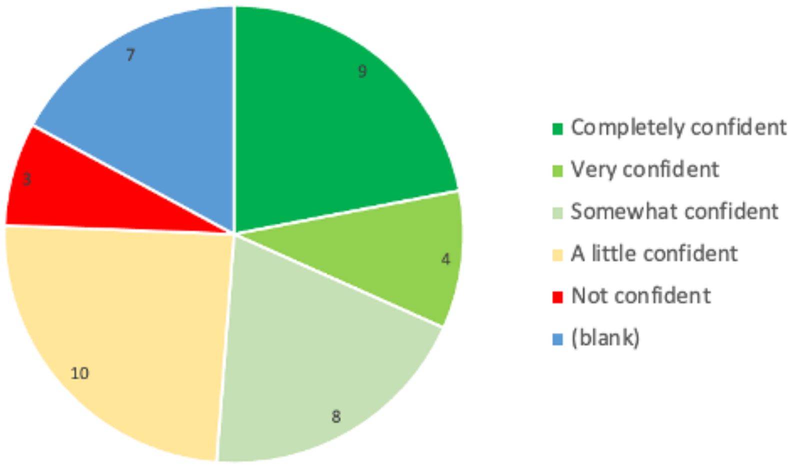
Supplement 12. "When your loved one with Down syndrome has been referred for a diagnostic test or appointment, have you worried about any of the following?" N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

13. Gender, racial/ethnic, and cultural/religious concordance



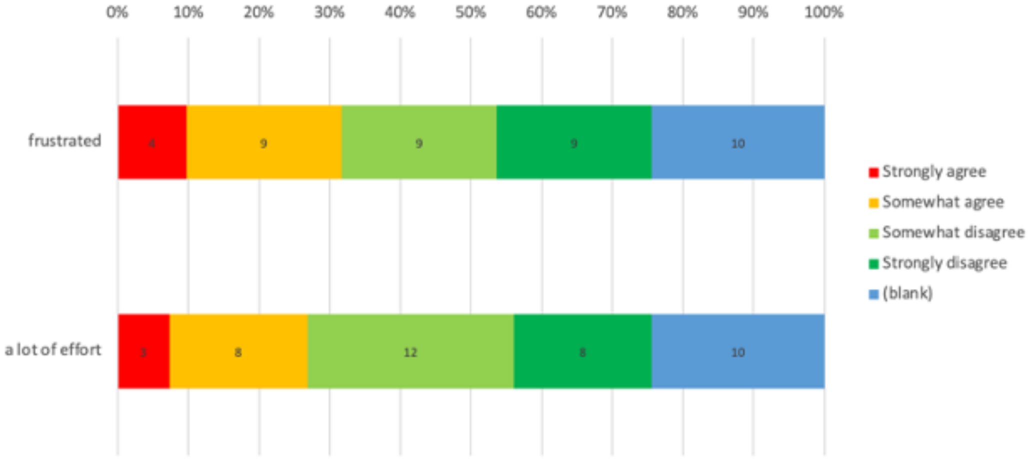
Supplement 13. "In general, how important is it to you to have your loved one be cared for by…" N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

14. Confidence related to getting advice or information about Down syndrome



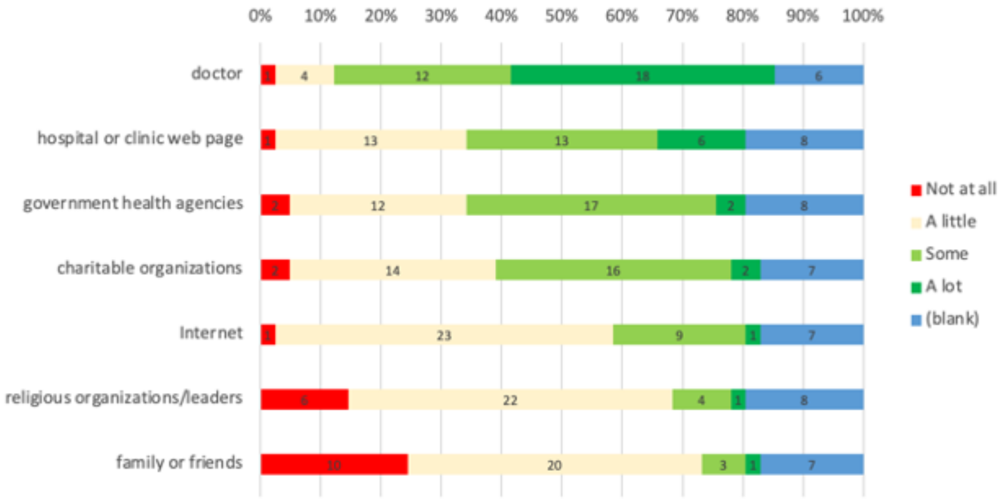
Supplement 14. “Overall, how confident are you that you could get advice or information about Down syndrome if you needed it?” N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

15. Experience with searching for information about Down syndrome



Supplement 15. “Based on the results of your most recent search for information about Down syndrome, how much do you agree or disagree with each of the following statements?” Two statements: “You felt frustrated during your search for information”; “It took a lot of effort to get the information you needed.” N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

16. Trusted sources of information about Down syndrome



Supplement 16. "In general, how much would you trust information about Down syndrome from each of the following?" N = 41 people with Down syndrome where Spanish is the primary spoken language at home, as reported by their caregivers (counts per response choice listed in bars)

17. Caregiver Focus Group: Trusted Sources of Information

Caregiver support groups	"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. They help me, too, when I started this path with my girl, I realized that there were no groups in Spanish in my area, and it is a very large area of Latinos, so I started my own group in Spanish in the area and, thanks to that, the two foundations that are here, the Down Syndrome Guild and the other also began to give classes in Spanish." "It's Down Syndrome Diagnosis Network…and it also has groups for everything. They are moms and dads and there are age groups, it's like every six months; It is a general one for all ages, there are groups in Spanish." "Again, I think it has been very important to establish contact with organizations like Massachusetts (MDSC), because they have that portal where one can communicate from pregnancy, one can make a call and can establish that type of contact, and be able to even chat with other moms, if you want to. And for me, above all, in my personal journey, what has helped me the most is meeting other moms, especially seeing other moms, seeing other children who have completely normal lives, as far as possible. There are many resources that they provide us now, they are ordinary families, with different challenges, but who know how to cope with situations and who succeed. So for me that has been very comforting, and for me, thus far, it is. I see older children, I see teenagers, I see adults, and so on. We, if we can project as mothers to young people, for me, I think that this is very enriching, because it is direct information, it is not fiction, it is not learned, it is the stories of ordinary people, and who lead a life more like any other." "[The home page] for Massachusetts Down Syndrome Congress. Across them—there are different groups, most of them are in English, where they are subgroups. And most of all that way we also interact to communicate in terms of more local activities. We also have different groups where they are only for moms or that we use more to hold meetings only for moms where we have meetings, previously in person, monthly." "I really understand that this is the objective of social media, so that we, mothers, use it for that support. If it were used only for that, it would be the best, to give support and find each other."
Using Down syndrome resources for information	"Here in [our city] we have a Down syndrome clinic, so they are very supportive...they give you a list of likely specialists the child might need. That helped me a lot. The Down Syndrome clinic has helped a lot. Yes, there are many, many resources. Now that my daughter is also receiving a social worker from the health insurance, she is also always very vigilant. If I mention something to her, that I have noticed, she is always very aware of referring to me." "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."

“I do receive all the information from the Central Florida Down Syndrome Association, but I have not been to any activity...Online, I am very active with all that, and I know everything that happens, but I have not been to any activity. Because of the pandemic, I have not been able to physically integrate into any of the groups here in Central Florida.”