NC Initiative for Young Children's Social-Emotional Health and Development

Family Voice Report

NC Early Childhood FOUNDATION

NC Child
The Voice for North Carolina's Children

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Executive Summary

More than 200 North Carolina families who have or have recently had young children (birth through age eight) involved in the social-emotional health system shared:

- What helps them support their children's social-emotional health and development
- What they value in social-emotional health and development services and providers
- How they like to access services
- What a good partnership with their child's doctor or teacher would look like
- What barriers prevent them from accessing needed services
- What services they wish were available
- What they would change about the system or their experiences with the system
- Their experiences of racism and cultural competence in the system

This paper goes into detail on many themes from the families' responses. Even more importantly, it shares direct quotes from the parents and caregivers interviewed and surveyed, illustrating those themes. We encourage readers to spend some time with the full report. Immersing ourselves in the voices of parents and caregivers can provide support for some of our prior beliefs about families' experiences *and* illuminate our blind spots. Centering families' voices and experiences is critical as we work to build a better social-emotional health and development system for young children in North Carolina.

Themes from the report include:

Healthy, well-adjusted parents are the most important resource for young children's social-emotional health and development. Nearly every respondent said that they themselves were their children's primary support in social-emotional health and development. (See page 7)

The people surrounding families with young children are also important resources. A wide variety of family, friends, social groups, and professional providers of services were noted as helping to support young children's social-emotional health and development. (See page 10)

There is a wide variety of services and programs that respondents either do not currently have access to or that they feel there should be more of, from community-based play and learn programs for young children to resources for families who do not speak English to mental health therapy for parents. (See page 12)

The things that families value most in providers are people skills and compassion. Families need providers to communicate well, be understanding and supportive without judgement, be caring, engage with them in a sustained and genuine way, be trustful and trustworthy, be respectful, work well as a team, personalize services, and be linguistically and culturally competent. (See page 12)

Families are very concerned – at times panicked, at times despairing – about being able to access needed services, including being aware of them, having them available nearby at workable times and having transportation, affording them, being eligible for them, and having them be flexible. (See page 21)

Families are much less worried about the quality and reliability of services, though those themes did come up, as did **parent choice of services**. (See page 35)

Other barriers that prevent families from accessing services include frustration with their children being labeled, not feeling comfortable seeking help, and additional pressures like being stretched too thinly to take advantage of services, and struggles with mental health, addiction, domestic violence, COVID-19, and family economic security. (See page 37)

Respondents of all races reported incidents where they felt they had been treated differently because of their races. In addition, experiences of racism in the system were likely underreported because of cultural taboos as well as unavoidable power dynamics at play during the interviews and surveys. (See page 44)

There were some differences by race/ethnicity, income, and gender in experiences with the system, what is most valued, and biggest concerns and barriers reported. (Throughout report)

Finally, **respondents also shared their experiences with specific sectors of the social-emotional health ecosystem**, including:

- Perinatal supports (page 54)
- Home visiting and other in-home supports (page 55)
- Parenting education and community-based supports (page 59)
- IDEA Part C/Early Intervention (page 64)
- IDEA Part B/Exceptional Children (page 69)
- Care management (page 72)
- Medical home (page 74)
- Health insurers (page 83)
- Evidence-based programs (page 86)
- Early education (child care, preschool and K-3 elementary school) (page 92)
- Foster care (page 101)
- Ecosystem supports (page 109)

Introduction and Respondent Demographics

> "In general, social-emotional support is necessary for everybody, and it can be hard to convince someone that they can need it because it is not really there for the broad scope of folks."
>
> "A good partnership should look like: we want this child to heal and live, like go live your life. Not the people who see him as a number or a bed."
>
> "I would like more information on trauma, and helping him deal with relationships with peers. Need to get to the root of the problem much earlier to help the child. [It should] be easier to get help without waiting so long."

In the late summer and early fall of 2020, the NC Early Childhood Foundation, in partnership with NC Child and four family provider organizations, surveyed and interviewed North Carolina parents with young children who have interacted with the social-emotional health and development system, defined as including the following sectors:

- Perinatal supports
- Home visiting and other in-home supports
- Parenting education and community-based supports
- IDEA Part C/Early Intervention
- IDEA Part B/Exceptional Children
- Care management
- Medical home
- Health insurers
- Evidence-based programs
- Early education (child care, preschool and K-3 elementary school)
- Foster care
- Ecosystem supports

The survey and interview protocols are available as Appendix A and Appendix B.

Two hundred thirty-four (234) parents or caregivers were interviewed (96) and surveyed (138) by our partners, four community-based organizations:

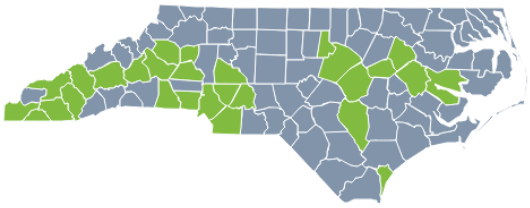
- Charlotte Bilingual Preschool is a Spanish bilingual preschool in Charlotte (Mecklenburg county)
- Families Moving Forward supports homeless families in Durham (Durham county)
- Family Support Network supports families with children who have special needs across NC. For the project, NCECF and NC Child worked with four regional FSN programs:
    - FSN/HOPE (serving Alexander, Burke, Caldwell, Catawba, Lincoln, and McDowell counties)

    - FSN of Eastern NC (serving Pitt, Beaufort, Martin, Greene, Lenoir, Hyde, Edgecombe, Wilson, Nash, Johnston, Craven, Carteret, Pamlico, Jones, Bertie, Halifax, Northampton and Wayne counties)
    - FSN of South Eastern NC (serving New Hanover, Brunswick, Pender, Columbus, Duplin and Bladen counties)
    - FSN of Southern Piedmont (serving Cabarrus, Iredell, Rowan, Stanly, Union, and Gaston counties)
- Passage Home works with families in Raleigh (Wake county) to reduce poverty and promote economic self-sufficiency

Geography

Respondent families represented at least 28 different counties in NC (16 respondents chose not to identify their counties).

- The sample was less rural than NC as a whole: 72% of the sample was in a non-rural county, as defined by the NC Rural Center, compared to 60% of North Carolinians overall.
- Counties represented included: Alexander, Beaufort, Buncombe, Burke, Cabarrus, Caldwell, Catawba, Cherokee, Clay, Cleveland, Durham, Edgecombe, Gaston, Haywood, Jackson, Johnston, Macon, McDowell, Mecklenburg, New Hanover, Pitt, Rowan, Sampson, Stanly, Swain, Union, Wake, and Wilson.



Race/Ethnicity

Compared with NC racial/ethnic demographics:

- Hispanic families were oversampled
- White families were under-sampled
- The samples for African American/Black, Native American, Asian, and two or more races more or less matched NC's demographics.

	Sample	NC 2019 Estimates
African-American/Black	20%	22%
Asian (Hmong)	<1%	3%
Hispanic	29%	10%
Native American	3%	2%
Two or more races/Other	3%	2%
White	36%	61%

Note: 9% of respondents chose not to identify their race/ethnicity

Language

The surveys were taken in English (65%) and Spanish (35%), and interviews were conducted in English (84%), Spanish (15%) and Hmong (1 interview).

- Spanish speakers were oversampled, and English speakers were under-sampled. As of 2019, an estimated 12% of North Carolinians over age five spoke a language other than English at home.

Income

The sample had lower income than the average NC household:

- Sixty-three percent of the sample has income under twice the federal poverty level, with 40% of those living in poverty. The poverty rate in NC overall is 14%.
- About a quarter of the sample (24%) are being served by Passage Home and Families Moving Forward, which primarily serve homeless families.
- The median income in NC is $54,602, which is higher than at least 67% of the sample, and most likely more. (NOTE: 25% of the sample chose not to share their income, or shared something that could not be translated into dollars, like “Just SSI” or “minimum wage.” Those who did not report their income therefore skewed towards the lower end of the income spectrum.)

	Sample	NC 2019 Estimates
Below 50% FPL*: below $10,860	19%	14%
50-100% FPL: $10,860-$21,720	19%	
100-200% FPL: $21,720-$43,440	25%	
200-300% FPL: $43,440-$65,160	7%	Median income = $55k
Above 300% FPL: above $65,160	5%	

* FPL = Federal Poverty Level for a family of 3

Note: 25% of respondents chose not to share their income

Gender

The sample was 86% female, 8% male, and 6% chose not to identify their gender.

Who and what supports children's social-emotional health and development?

Parents and caregivers were asked to share who or what has helped their children learn how to make themselves feel better when they are upset, scared or sad, how to talk about their feelings, and how to learn to form strong friendships.

Nearly every respondent said that they (the parent or caregiver) and often the child's other parent were the primary people to help their children learn these skills. They also highlighted the roles of grandparents, other extended family members, other children, the parents' friends, and professionals – specifically therapists and child care or school teachers.

By race:

- Respondents were nearly all much more likely to mention Mom as a support than Dad, but it should be noted that 95% of the respondents were female.
- White and Black respondents were more likely to mention grandparents or other relatives than Dad, while Hispanic respondents were more likely to mention Dad than extended family. Many Spanish-speaking Hispanic respondents noted that they didn't have extended family nearby.
- Most respondents were less likely to mention professionals than family members, with the exception of white respondents, who were nearly as likely to mention professionals as Mom, suggesting that white respondents have access to/rely on professionals more than respondents of other races.
- Most respondents mentioned their own friends and other kids much less often than family members, with the exception of white parents, who mentioned other kids frequently.

By income:

- Those with the lowest incomes (below 50% of the federal poverty level), followed by those with the highest incomes (above 200% of the federal poverty level) were more likely to mention professionals, suggesting they are more likely to have access to/rely on professionals than those in the middle-income brackets.

By homeless status:

- Though respondents being served by a homeless shelter and respondents not being served by a homeless shelter mentioned Mom, Dad, other family, and friends about equally, homed respondents were three times more likely to mention a professional than homeless respondents, suggesting homeless respondents are much less likely to receive consistent support from professionals like therapists and teachers.

Family voice on who or what supports your child's social-emotional health and development:

Mom and Dad:

Me. I confront my kids if they're upset. I don't think there is another option other than that.

-- PH_Interview 3

The most important is learning about the unique things the child does to be able to help them. The parents are the most important ones.

-- CBP_Spanish Interview 2

Dad and I. Most of the time they come to us when they are feeling a certain way. We listen and try to explain to them that it's ok to feel that way.

-- FSN_Interview 1

I am doing everything I can for him to teach him the feelings, but I need professional help.

-- FSN_Interview 41_Spanish

Other family members:

Sometimes my father from Guatemala helps

-- CBP_Spanish Interview 1

People that they can trust like grandmothers

-- FMF_Family 12

Our close family, like her two sisters, my brother, and my mom

-- PH_Interview 17

My husband's cousin gave advice when we talked to her about situations with our child

-- CBP_Spanish Interview 1

Other kids:

Each other. If one of them is sad, they do something to try to make them smile. They're all so close in age.

-- FMF_Family 7

Being around other kids in playgroups I took him to when he was little.

-- FSN_Interview 26

Our church family and his "older buddies" at church and his Sunday School teacher and friends from church.

-- FSN_Interview 34

Parents' Friends

He learns through the example that we give as parents and the friendships that we have.

-- CBP_Spanish Interview 3

My husband's best friend has kids around the same age. We've always just been around them as their best friends and the men show the kids how to be best friends. They're best friends but treat each other like family.

-- FMF_Family 6

We have a lot of friends who have children that are about the same ages. They see us moms have a good relationship so I think they learn from us. We all help each other in any way we can.

-- FSN_Interview 3

Professionals:

Currently, we're working with a CPS caseworker, so [child] has learned about feelings from case worker as well.

-- PH_Interview 15

Daycare helps kids a lot. My son, before he started going, he was so attached to me and I couldn't leave the room. Now that he is daycare he plays with other kids and isn't shy.

-- PH_Interview 14

Therapist helped with relationships, talked about how to get along with other kids. Teachers help with social skills by having the kids play games and doing things together.

-- FSN_Interview 20

My son had a psychologist that came to my house. She taught me methods to calm him down when he was upset and to learn how to understand his feelings. Since he was a little boy, he couldn't talk, and he was frustrated that I couldn't understand what he was trying to tell me.

-- FSN_Interview 40_Spanish

We've had many children where Intensive In-Home Services were provided so they had a team to help the child calm down and support them, along with services from the Mobile Crisis Unit provided. Each child we fostered had a mental health therapist in place who for the most part we were satisfied with and had a good rapport with the child and with us. A lot depends on how accurate the initial diagnosis was. If it was later determined to be wrongly diagnosed, this created major problems in the care and treatment for the child.

-- FSN_Interview 12_Foster

Beyond the people who have helped their children's social-emotional development, respondents also mentioned things like pets, faith, books, play, food, exercise, medications, TV, and coping strategies.

Food makes them happy. Their dog makes them happy. Getting out and walking makes them happy.

-- PH_Interview 8

He watches a lot of PBS kids. They help with conflict resolution. He quoted a TV show talking about how he couldn't hit because he was angry.

-- FMF_Family 23

We also read books and talked about what the characters were feeling.

-- FSN_Interview 24

His church has been very supportive and welcomed him. They were very flexible with his needs. He goes to an aftercare at his church. They give him principles of sharing and being kind. Also, church on Sundays helps him with peer support teaching him healthy habits emotionally and building friendships.

-- FSN_Interview 7

Who and what helps parents and caregivers as they support their children?

Parents and caregivers were asked to share who or what has helped them as a parent or family member to learn how to support their children's social-emotional health.

Respondents most often mentioned specific programs, their families, other parents (including moms' groups), therapy, child care/school, the internet, their faith, doctors, and parenting classes. A small handful of respondents mentioned caseworkers, advocacy, medication, library/books, mentors, and other kids.

- White respondents most often mentioned programs, family, therapy, and other parents, followed by their faith or faith communities.
- Black respondents most often mentioned programs, family, other parents, therapy, and child care/school. A good portion of Black respondents also mentioned the internet and their faith or faith communities.
- Hispanic respondents most often mentioned child care/school (it's worth noting that one of the four organization that conducted the interviews was a Spanish bilingual preschool), the internet, other parents, family, programs, and therapy.

Family voice on who or what has helped them as parents support their child's social-emotional health and development:

When we moved here, she did NC PreK. They helped me a lot and supported me a lot. When I was in the home visitation program, being able to speak Spanish to other parents was really helpful.

-- PH_Interview 7

Different programs, also Family Support Network, CMARC coming for my newborn helped with all my kids.

-- FSN_Interview 2

My mom, my sisters. My family has overall been supportive. Help me anyway they can. If I need someone, they are there. They gave me a break when I need one.

-- PH_Interview 14

The information I received from a friend, she told me that this benefit was available and that I didn't have to wait until my child was 3 years old, even though that is what my pediatrician said when my son was 18 months old. My friend said that no one knows your child better than you. Tell your pediatrician that you need a specialist.

-- CBP_Spanish Interview 7

Some places are just like "You need to be strong for your kids." It would be helpful if more people reached out and just asked "Are YOU okay?" My counselor I can reach out to anytime and she will listen and help me with things like that. I think it is important to have a therapist or counselor to talk about your feelings separate from your child. I feel most comfortable in an individual setting rather than in a group setting.

-- PH_Interview 13

One-on-one time with a counselor would be great, because sometimes the parenting classes don't help.

-- PH_Interview 17

The help that I received was when my child was little, through speech therapy. The therapist helped me a lot as well as my son. And the therapist helped us recognize that our experiences make us act in certain ways as parents.

-- CBP_Spanish Interview 7

Teachers. My oldest son had a really hard time in daycare. They gave me ideas. They even came to have someone observe my son to see if he qualified for extra services.

-- PH_Interview 6

I started following a therapist on social media because she gives so many good tips about social emotional health. Social media is the best way for me to learn things about social emotional health. I follow therapists and psychologists. Social media is easy for me to learn on the go.

-- PH_Interview 7

I use the internet with links to all kinds of resources from people I've met from the Autism society.

-- FSN_Interview 7

Mommy groups with different techniques (Pregnancy/Post Partum group, "Sis are you in need? I can help you" etc. – found on Facebook).

-- FMF_Family 3

Ladies from church have really stepped up to help me. When I was in a car accident the ladies from church helped to drive me places and helped to make us food.

-- PH_Interview 3

His nutritionist has helped me a lot. She has always showed that she truly cares about me and my family. She helps get information about resources.

-- FSN_Interview 6

Pediatricians. They always ask if I need help and offer advice.

-- PH_Interview 6

I take medication for emotional and mental health, if I didn't have that it would be kind of scary.

-- PH_Interview 12

Library: I use the library to help with learning. The librarian helped teach my daughter to read and gave lots of tips. We use the children's room, reference room, and the computer. We use ABC Mouse on the computers a lot.

-- PH_Interview 3

What is missing in the social-emotional health ecosystem?

Respondents were asked to share what types of programs, services, or supports they wished were available and easy to get to help them support their children's social-emotional development.

Respondents shared a wide variety of services and programs that they either do not currently have access to or that they feel there should be more of, including (in the order of number of times they were mentioned): community-based programs and other programs just for kids, therapy, child care, programs to develop children's social skills, support groups, resources for families whose first language is not English, system navigators, services for children with disabilities, services for foster families, respite services, information on child development for parents as well as general information/awareness of available services, family income supports, remote learning, home visiting services, birth supports, and supports for grandparents.

It is important to note here the large range of services and supports that parents would find helpful. A sampling of these comments from respondents are shared below in the section of the report that addresses families' experiences with specific sectors of the social-emotional health and development ecosystem.

What do families value in social-emotional health services and providers?

In order to understand what families value in a relationship with a provider, respondents were asked: What would a good partnership between you and your child's doctor, teacher, or support person look like and feel like?

Families value:

- **Communication** between families and providers
- **Understanding** of their situations and **support without judgement**
- **Caring** providers
- Providers' sustained and genuine **engagement** with them and their children
- **Trust** among parents, children and providers
- **Respect** for their important role as parents and family members
- **Teamwork** among the providers serving their children/family
- **Personalization** of services; no "one size fits all"
- Their children's **growth** as they use the services
- **Linguistic and cultural competence** of service providers

Nearly all respondents also answered yes to whether "**feeling understood** by the people helping you and your child was important for you to receive the feedback offered."

It is 100% important. They need to know where I have been, where I am coming from, and where I would like to be.

-- PH_Interview 3

It is very important to us to have people who are understanding who help us. We need to know whether they are here to help us or get us out of the way. It is very important because we want to know how to better our lives.

-- PH_Interview 8

That matters a lot because it is a thin line where the person receiving the help could feel like they are being judged and less than. So that is really important.

-- FMF_Family 28

It matters. If I don't feel comfortable in a place, most likely I won't like to come back.

-- PH_Interview 6

I want to be understood because I'm asking for help for my son. I want them to know what kinds of help I'm looking for so we can work together to make my son's experience better in school and in the community. I am the biggest advocate for my son.

-- FMF_Family 30

It is important. It matters to me that I know that the person helping me really wants to support me. It helps me to have that reassurance that you're going to help me to your best ability and not just brush me off. How you treat my child is important, very important. That will stop you from doing a lot of stuff. That will stop you from wanting to talk to anybody. I don't want to be a burden on anybody. If I see you don't care, that's going to impact.

-- FMF_Family 4

It is very important, because being Hispanic sometimes I feel left out and for them to make me feel that we all are the same made me feel very good about myself.

-- FSN_Interview 3

Yes, it's important to receive welcome.

-- FSN_Interview 42_Hmong

In addition, all subgroups of respondents were highly likely to note **communication** as an important aspect of a good partnership with a provider.

Communication is the key—without communication you have nothing.

-- PH_Interview 9

Letting me know what's going on – goes for both doctor and teacher.

-- FMF_Family 15

A relationship where it's safe to raise questions and where there's open communication where progress is shared.

-- FSN_Interview 13_Foster

People who have good, honest conversations to tell me about his behavior so that we can address any issues rather than just saying he was fine. Being able to talk freely without being judged and feeling supported.

-- FSN Interview_31

Open discussion. Being heard. Being able to talk things through things, not just be given instructions.

-- FSN_Interview 26

Communication needs to be very clear. There needs to be more explanation of the programs when they put you in it. You need to know what you are going to get out of it and how to make progress. They give help but I seem to be in the same situation as before.

-- PH_Interview 8

For them to listen to you.

-- CBP_Spanish Interview 5

Being able to communicate and trying to work together. Communication and the vibes would be different. The attitude, body language, etc.

-- FMF_Family 13

Communication – making sure that we understand. Nodding your head doesn't mean understanding – it is just about respect.

-- FMF_Family 5

After **communication** and **feeling understood**, here are the other values highlighted by respondents:

By race: Care, trust and engagement were popular among respondents of all races.

> Black respondents were more likely that those of other races to mention wanting providers to genuinely **engage** with them and their children, and for providers to show that they **care**, followed by **trust.**

They need to be more concerned and not just doing a job. If the person cares, she can make a difference in our life. Just be a little more caring, concerned, and going the extra mile for a family who is facing a tough situation. Even if you're not going to help me, if you seem concerned and seem like you have done everything you can I'm cool with that.

-- PH_Interview 8

His early intervention team – his pediatrician and his early education coordinator from CDSA were overwhelmingly warm and comforting and resourceful.

-- FMF_Family 6

Listening when you tell them that stuff is going on.

-- PH_Interview 2

I feel like she really understood where I was coming from and she handled it rather than telling me I had to call this person and that person.

-- FMF_Family 12

Hispanic respondents were highly likely to mention that they wanted to feel that providers **cared** about them and their children, followed by **engagement**, **trust**, and **linguistic and cultural competence**.

The teacher was very understanding, that is the support and the relationship I need.

-- PH_Interview 7

It is important that when you look for help, people are compassionate because sometimes they don't know all of the problems and they become part of it. When there is trust it is much easier.

-- CBP_Spanish Interview 3

We have felt welcome at school. It takes one person to make a difference and be interested in your culture.

-- PH_Interview 7

Who helped me most was the pediatrician and later the lady from the service provider who speaks Spanish. She is always available and helpful, and every month she is observing to see how therapy is going.

-- CBP_Spanish Interview 1

Native, Asian and respondents of more than one race were most likely to mention **engagement** as really important, followed by **care** and **teamwork**.

Finding a doctor, teacher or someone who is honest and can explain things carefully so you don't have to try to figure things out on your own. Finding someone who really listens and seems to care about your child and is not too busy to spend time with you. Helping parents not feel like they are alone, if that they don't know how to deal with their child's behavior the right way.

-- FSN_Interview 36

Partnership for my child is helpful.

-- FSN_Interview 42_Hmong

White respondents were much more likely than those of other races to mention wanting to feel **respected** by their providers and wanting to feel like there was **teamwork**. They also wanted to experience **care**, **trust** and **engagement**.

A big thing is that they respect you. Especially when dealing with addiction and motherhood, it really helps when they treat you just like anyone else. Not undermining, belittling or minimizing. Even if they don't actually care, acting like they care! And not that they are just doing their job and checking the clock.

-- PH_Interview 13

Understanding that I'm the mom and I know her best.

-- FSN_Interview 19

Having a listening ear and be encouraging, not judgmental.

-- FSN_Interview 39

Open communication both ways and receiving prompt responses and being open to find ways to help the girls. We now have a good team working with us who understand our situation.

-- FSN_Interview 37

A great relationship is important because he notices who likes him and who doesn't. He can tell who listens to him and who wants to talk to him. He is very social, and people are important to him.

-- FSN_Interview 34

Trust needs to be there—2 way trusting relationship.

-- PH_Interview 15

By Language:

> Respondents who spoke a language other than English were much more likely than English-speaking respondents to note **communication** and **linguistic and cultural competence** as of primary importance.

Sometimes, they don't listen to you. They did not sit down and listen, it was just based off a questionnaire. The doctor asked questions and told me to do what I was already doing.

-- CBP_Spanish Interview 5

Lack of communication with the pediatrician is also an issue. The appointment is very short. Sometimes I didn't have time to ask the questions that I had. Giving more time to the patient, and listening to me, not just me listening to him.

-- CBP_Spanish Interview 7

Trust and communication. The way they talk to me is very important. I don't really understand English and sometimes it's hard for me to understand and process what I'm being told. I feel sometimes they (school staff) gets frustrated with me because of the language barrier. They have made me feel uncomfortable. I just wish they would be more patient and understanding.

-- FSN_Interview 1

I ask a lot of questions and sometimes teachers and doctors don't want you to ask them questions. To be (able) to ask anything about your child, wherever, at school or the doctor.

-- CBP_Spanish Interview 4

A guide or tutor that can help you find the services you need in various areas and help you make sure you receive them, rather than having to work through everything alone. It would help if the guide spoke Spanish and understood your culture and background.

-- CBP_Spanish Interview 6

By Income:

> Those living in deep poverty (less than 50% of FPL for a family of three) are most likely to mention the importance of feeling like providers **care**.

Everyone being on the same page. That's really big. Having the right people around. People that genuinely have our best interests at heart. People that are understanding and patient because we are a lot of work and we require patience.

-- FMF_Family 23

Just being kind, generous.

-- FMF_Family 9

These parenting groups, Caring Connections. It is like they don't acknowledge that you are an addict. They just talk to you like you are anyone else, they talk about motherhood without always bringing up the addiction. If you feel like they don't understand you or your situation or are judging, you have reservations about telling them things or listening to what they have to say.

-- PH_Interview 13

Those living just below the poverty level are most interested in **teamwork** and **care**.

Partnership. Collaboration – a team approach. Treat it like a business. Creator: Mom. Marketing Firm: providers. Business of the day: goal. More commonality with people when things happen. More understanding, more bonding.

-- FSN_Interview 28

Teamwork is very important, and effective communication. I would like everyone to work together – the doctor, the school, the private therapists, all together, an integration of all the services.

-- FSN_Interview 40_SP

When you have a child with special needs, all you can think of is your child. You don't have time to think about yourself. So I would have to say it was a nice gesture when his nutritionist ask how I was doing, how was I feeling? She made me feel good. She always cheers for me. She tells me I'm doing a good job, that I'm a good mom. No one ever asks me, not even my family.

-- FSN_Interview 6

Those living between the poverty level and twice poverty are focused on **trust**, **engagement**, and **respect**, followed closely by **care** and **cultural competency.**

Feel comfortable reaching out to them if you have any issues. If you don't feel comfortable, you just don't want to talk to them at all.

-- PH_Interview 11

When I have a question, I want honest talk back.

-- FSN_Interview 14_Foster

The therapist has been available and helpful in several ways, even for small things.

-- CBP_Spanish Interview 1

The person who carried out the process was very attentive to me and my child and I felt good.

-- CBP_Spanish Interview 2

When the doctor takes extra time to really listen and speak with me.

-- FSN_Interview 14_Foster

That they treat my daughter with respect.

-- CBP_Spanish Interview 6

Those at 200-300 percent of the poverty level mention **care** most often, followed by **respect**, **engagement**, and **teamwork.**

They need to have empathy. They felt they were listening to me but I felt they weren't actually taking what I say into consideration. I said I am not denying my child is doing that but he isn't doing that at home. And I told them I was confused.

-- PH_Interview 6

For them to listen to you, to understand you, for them to help you find someone who does it.

-- CBP_Spanish Interview 5

Just being able to reach out and connect in those difficult situations and just being accessible. I've never had an experience where I couldn't connect with someone.

-- PH_Interview 10

Collaborative care. You have to repeat yourself everywhere you go – school needs, doctor's needs, etc. One care team approach. Everyone knows what part they play in the care process, explain what each provider covers, to achieve positive results for the child. They need to be open hear what parents and other providers are saying not just what they do.

-- FSN_Interview 22

Those in the highest income bracket (more than three times poverty) highlighted **engagement**, **trust**, and **personalization**, followed by **care** and **respect.**

Current primary care doctors roll out the red carpet for him. They worked with her fears. Gave her reassurance. She was afraid of going into the waiting room with her baby so she would wait in the car. They would call her when it was their time. They spent time with her and were always current with the information about her son. If she called the office with a question the doctor always returned the call. Being accessible, listening, optimistic/positive attitude, feeling valued. Able to make own decisions and not feel judged. Respecting each other's boundaries.

-- FSN_Interview 21

Ninety percent if the time I felt the pediatrician understood my struggles. It was mother to mother. She understood my problem adjusting from one child to two. She knew what I needed to hear had good insight. She really cares. It shows in her eye contact, tone, and gestures. She shared her personal story about her adjustment to a new child. She empathized with me. Listen, care about what I am saying and understanding me. If they do not care they are not worth my time.

-- FSN_Interview 24

The family survey included questions about feeling welcomed, valued and understood, and about linguistic and cultural competence. The following charts share respondents' ratings on the questions, disaggregated by race/ethnicity (including Latinx-English speaking and Latinx-Spanish speaking), income, and gender. Please note that sample sizes (n) for some categories were very small.

It is important to me that I receive services for my child from someone or an agency that makes us feel welcomed

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	81.8%	83.3%	92.9%	64.1%	40.0%	98.0%
Agree	15.3%	8.3%	7.1%	30.8%	60.0%	2.0%
Disagree	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Strongly Disagree	2.9%	8.3%	0.0%	5.1%	0.0%	0.0%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	88.0%	71.9%	86.7%	76.9%	88.9%	71.4%
Agree	12.0%	21.9%	6.7%	23.1%	11.1%	21.4%
Disagree	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Strongly Disagree	0.0%	6.3%	6.7%	0.0%	0.0%	7.1%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

This item received the highest ratings of any question on the survey, with 97% agreeing (and 82% of those strongly agreeing).

- Race: All the Latinx (English-speaking), white, and Native American respondents agree/strongly agree (with 98% of white respondents strongly agreeing). 95% of Latinx (Spanish-speaking) and 92% of Black respondents agree.

- Income: All of those at the ends of the spectrum thought this important (extreme poverty, and over 150% of poverty). Slightly fewer (93%) of those closer to the poverty line (just below and just above) focused on this.

- Gender: 93% of male respondents agree/strongly agree, less than the overall.

It is important to me that I receive services for my child from someone who values my experiences and opinions

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	60.1%	46.2%	71.4%	51.3%	60.0%	69.4%
Agree	31.9%	38.5%	28.6%	41.0%	40.0%	22.4%
Disagree	5.1%	7.7%	0.0%	2.6%	0.0%	8.2%
Strongly Disagree	2.9%	7.7%	0.0%	5.1%	0.0%	0.0%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	56.0%	59.4%	66.7%	50.0%	80.0%	35.7%
Agree	36.0%	25.0%	26.7%	46.2%	20.0%	42.9%
Disagree	8.0%	9.4%	0.0%	3.8%	0.0%	14.3%
Strongly Disagree	0.0%	6.3%	6.7%	0.0%	0.0%	7.1%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

This item was ranked very highly overall, with 92% agreeing/strongly agreeing:

- Race: Black respondents (84%) were least likely to report that this was important to them. About 92% of both Latinx respondents in Spanish and white respondents agree/strongly agree. 100% of the Native American and Latinx respondents in English agree/strongly agree.

- Income: Those just under the poverty line are not as focused on this (84%) as those just above the poverty line (93%) and those in extreme poverty (92%). Those in the highest income bracket felt the most strongly about this item, all agreeing (80% of them strongly).

- Gender: 78% of male respondents agree/strongly agree, fewer than the overall.

What are the barriers to accessing social-emotional health services?

When asked about what things have made it difficult for them to access programs, services or supports for their children's social-emotional development in the past or right now, families talked about:

- **Accessibility** of services, including:
    - Families' **awareness** of what services are available and how to access them
    - **Availability** of services near their home, without waitlists, including need for **transportation** to access the services
    - **Affordability** of services
    - **Eligibility** for services
    - **Flexibility** of providers/organizations, especially in terms of scheduling (see Good buckets)
- **Choice** of services
- **Reliability** of service providers
- **Quality** of service providers
- Their frustration with their children being **labeled**
- Needing a **break**, or respite
- Not feeling comfortable **seeking help**
- Their own struggles with **mental health, addiction, domestic violence, COVID-19, family economic security, and the justice system.**

Families' report of **accessibility** of services, including awareness of services available, and availability, flexibility, eligibility and affordability of services, and need for transportation differ some by income level and by race.

- **Availability** of services was one of the top issues reported by respondents of all income brackets and all races.
- Those in the lower two income brackets (below poverty) also reported **awareness** of services and **transportation** as top issues. Same for Asian, Native American, and respondents of two or more races.
- Those just above the poverty level also reported **awareness** of services and **flexibility** of services as top issues. Same for Black and Hispanic respondents.
- Those in the top two income brackets (more than twice the poverty level) also reported **affordability** and **eligibility** as top issues. Same for white respondents.

Awareness

Family voice on need for more awareness of what services are available:

Just not knowing what is out there. I feel that the doctor should let you know of services such as PAT, CC4C, or P2P.
-- FSN_Interview 3

It is hard to find resources for behavior problems. Lack of equal knowledge at agencies: It is easy to get a phone number for a resource but that doesn't mean you will talk to the right person. Since being at ***, they do provide you with a lot of resources if you have certain concerns. Before, when it was just me, it was a lot harder to find the resources. It was mostly just Google, and sometimes it took calling a lot or pressing a lot of buttons before you can even talk to a person. Here at *** they will just hand you a list of resources. Why can't it be that helpful at Social Services? They should have lists of things that were available to people locally.

-- PH_Interview 3

More education to families about how to find resources as soon as possible after their child is born if they have concerns and to get them evaluated early to put the resources in place so that their child can be more successful and have less social-emotional issues before they reach kindergarten.

-- FSN Interview_31

Sometimes, as grandparents it is harder to get services for him, but so far, we have been able to get him the help he needs. Things are just so different than when we raised our children and we don't know what services are available to him.

-- FSN_Interview 34

I wish there was a simple system to disseminate information such as identifying what resources are out there for what needs/services. All these think tanks are great, but they are not accessible for me to get through this sea of unknowns.

-- FSN_Interview 12_Foster

A more robust support group in the community, a larger network, parent-to-parent, counselors for parents with special needs family member. Didn't find out about FSN till a few months ago. It would be good if other services knew about it and gave out information.

-- FSN_Interview 23

I like the psychologist we found and the therapist was helpful, but I had to do the research to find them.
-- FSN_Interview 26

Awareness was particularly brought up by Spanish-speaking respondents:

Education for families from other countries to know that services are available and how to access them. Having a place that you can go to get information about where the services and resources are, what they do. A guide or tutor that can help you find the services you need in various areas and help you make sure you receive them, rather than having to work through everything alone. It would help if the guide spoke Spanish and understood your culture and background. The services and programs had not been extended to everyone, just a few people who knew about them and used them. It needs to change so that information can get to everyone, so that at everyone could participate.

-- CBP_Spanish Interview 6

I wish that they were more publicized and more talked about. I don't know if it is different between brown and white people. The information I received from a friend, she told me that this benefit was available and that I didn't have to wait until my child was 3 years old, even though that is what my pediatrician said when my son was 18 months old. My friend said that no one knows your child better than you. Tell your pediatrician that you need a specialist.

I ask myself why there weren't advertisements for these things outside of the clinic. In the past, I didn't know they existed or that there were supports that would could use. The constant lack of information was a problem. Now I am making use of the benefits. If it had been easier to find benefits, I would have found them before. At school there is an advisor, but within the school I don't know what they do about that. It is important that there is more information, that families know and pediatricians can facilitate this more. I filled out many forms. It was overwhelming, and honestly I didn't understand.

-- CBP_Spanish Interview 7

The way the information is given out. There are a lot of services and programs that I'm not aware of. I know there are a lot of brochures out there but I feel us (Hispanics) are more unlikely to pick one up. Most doctors' offices have a TV, maybe it would be a good idea if they would post programs and services on there so we can automatically see it. Or maybe the doctor could mention a couple at the time of visit.

-- FSN_Interview 1

It's hard to access programs. You have to look for services because nobody is going to do it for you.

First that parents receive orientation of existing services, accessibility and uniformity including the integration of the services that the child receives. Understand how services work, how to use them. And within the socio-emotional services they will provide orientations to people who provide public services to the community such as firefighters, police, etc.

-- FSN_Interview 40_SP

The family survey also asked about whether **awareness** or **understanding rules** were barriers to accessing services:

	I haven't heard about these services?	I don't understand the rules about how to get services?	Number Surveyed
All	36.2%	8.0%	138
African American/Black	23.1%	7.7%	13
Latinx (English)	28.6%	0.0%	14
Latinx (Spanish)	48.7%	5.1%	39
Native American	20.0%	0.0%	5
White	32.7%	14.3%	49
<50% FPL	40.0%	8.0%	25
50-100% FPL	50.0%	3.1%	32
100-150% FPL	13.3%	13.3%	15
150-200% FPL	38.5%	0.0%	26
>200% FPL	10.0%	10.0%	10
Male	42.9%	7.1%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Overall, not hearing about services was marked the most often of any of the 29 reasons for not using services that families were asked about on the survey. More than a third of respondents noted that this was a problem for them. Not understanding the rules was not a barrier that resonated with many respondents.

- Race: Nearly half of Latinx respondents in Spanish hadn't heard of services. This large response is supported by what we learned in the interviews. A third of white respondents and nearly 30% of Latinx respondents in English hadn't heard about services. About a quarter of Black respondents hadn't heard about services. White respondents were more likely than respondents of other races/ethnicities to note that they didn't understand the rules about getting the services (14%). There were only five Native American respondents, and one of them noted that (s)he hadn't heard of services.

- Income: For those in extreme poverty and for those just under the poverty line, the main issue by far was that they hadn't heard about the services (40% and 50%, respectively). Many of those at 150%-200% of poverty had not heard of the services (nearly 40%).

- Gender: For men, the main issue by far (43%) was that they hadn't heard about the services.

The survey also asked respondents about how they would like to learn about services:

	Would you use information online?	Would you use a pamphlet or an app?	Number Surveyed
All	60.1%	44.2%	138
African American/Black	69.2%	46.2%	13
Latinx-English	57.1%	28.6%	14
Latinx-Spanish	43.6%	28.2%	39
Native American	80.0%	80.0%	5
White	71.4%	53.1%	49
<50% FPL	68.0%	56.0%	25
50-100% FPL	68.8%	37.5%	32
100-150% FPL	33.3%	40.0%	15
150-200% FPL	61.5%	46.2%	26
>200% FPL	90.0%	50.0%	10
Male	57.1%	50.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Using information online is the highest response, at 60%. Fewer than half (44%) would use a pamphlet or app.

- Race: Native (4 of 5 respondents), Black, and white respondents (about 70%) are more interested in getting information online than other races/ethnicities. Latinx respondents (in both English and Spanish) are less interested in a pamphlet or app (28%), while more were interested in online. Just over half of white respondents were interested in an app (53%).

- Income: Most income groups were interested in getting information online, except for those right around the poverty line. Nearly all of the respondents in the highest income category were interested in online information. There was less interest in an app – less than 50% in each income bracket – with the exception of the lowest income category, where slightly more than half were interested.

- Gender: Getting information online received the highest response for men, but lower than the rates from all respondents. About half of male respondents would use an app/pamphlet, which is lower than the rates for all respondents.

Availability

Family voice on the need for more availability of services:

Most services are for people with substance abuse difficulties or [who have] experienced domestic violence. There aren't services for single mothers just trying to get help and trying to get by. More programs for single parents – more shelters, help with child support, food resources, clothing resources.

-- PH_Interview 11

I feel most comfortable in an individual setting rather than in a group setting. Sometimes here the other girls don't get along, so I think that more individual sessions would allow people to talk about their concerns.

There are more things here in *** County than there were in *** County. There really weren't many resources there, because it is mostly little towns and farmland. It was a lot harder finding resources out there.

-- PH_Interview 13

There are no resources for kids his age. He is 2. I just wish I could have gotten him into a place and he would get help while he was younger. I just wish there were more resources for younger kids. [There are] waitlists to get into resources.

Waiting period. Everything is a waiting period. There is a wait list for everything. I had to wait in order to get on list.

-- PH_Interview 15

First they call you, then they schedule the appointment, and you just lose interest after such long time.

-- CBP_Spanish Interview 5

The processes here are terrible and take forever. This month is one evaluation. The next month another evaluation. and so on and you wait 3 months or more to even begin services.

There should be more bilingual early childhood centers. Tutors or guides to help people navigate that system. They should understand the Hispanic community and make the system make more sense to the Hispanic community. The services and programs had not been extended to everyone, just a few people who knew about them and used them. It needs to change so that information can get to everyone, so that at everyone could participate.

-- CBP_Spanish Interview 6

We lived in other states before and they offer far more services.

-- FSN_Interview 20

Wish they had access to a developmental classroom before age three. Living in a rural community not in the proximity of services [has been a barrier].

-- FSN_Interview 23

It was difficult waiting to begin the process because it took a long time. Not enough doctors, then they were not taking new patients. There was a long time on a waiting list - getting an appointment took months on a waiting list for a doctor. There needs to be a way of getting child seen sooner. Once she entered the process it was helpful.

-- FSN_Interview 25

It also took a very long time to get an appointment. We waited 6 months for the first meeting then another month in between the first and second session. The wait time for the good providers is so long especially for an initial appointment, and there is a lack of options for specialty care.

-- FSN_Interview 26

I did learn about the Innovations waiver grant through the resource café website now but it is a long wait.

-- FSN_Interview 7

I wish there were sibling programs to help his brother also and that services would be more local and cost would not prohibit our participation in them. We need opportunities to be with other families going through lots of things we are going through.

-- FSN Interview_31

I wish more services were available to let families know what services are local and we don't have to travel to Charlotte or Winston Salem.

-- FSN_Interview 36

Shorter wait times and more choices for parents.

-- FSN_Interview 39

Flexibility/Accessibility, including Transportation

Family voice on need for services to be more flexible/accessible:

Location—there isn't flexibility in where to meet.

-- PH_Interview 4

Timing—working and finding time to access the services is sometimes challenging.

-- PH_Interview 9

People would call, but it would be a bad time.

-- FMF_Family 10

Everything is far away. Work schedule makes it difficult to have the time to travel to them.

-- FSN_Interview 20

It is not always possible for to go to an office for an appointment. It becomes a barrier.

-- FSN_Interview 24

Once when living in low-income housing, people were concerned about coming to work with him or even deliver supplies.

-- FSN_Interview 38

Family voice on need for transportation to/from services:

Also, finding reliable transportation can be hard. Here they do have some bus routes, but where I am from in *** County I had to pay and call an Uber just to get him to Medicaid. If you live in the middle of nowhere even then you have to wait forever to get picked up.

-- PH_Interview 13

Transportation to doctor's appointments and to my child's events.

-- PH_Interview 3

Transportation is a big one—make it more massive—improving the infrastructure around transportation.

-- PH_Interview 4

There are many barriers to building relationships with others, like the language, cultural barriers and the lack of transportation.

-- CBP_Spanish Interview 6

At the beginning it took a month or more and I didn't have a car during that time. They talked with my husband and with me and eventually they came to the house. I never knew that they could provide transportation, I had always had to get a ride.

-- CBP_Spanish Interview 7

Better daycare with transportation.

-- FMF_Family 11

I would say transportation back and forth to doctor's office. You have to call so many days in advance, having transportation if kids miss bus. Having better ways to get kids back and forth to school.

-- FMF_Family 18

Pandemic and less access to transportation. Not wanting to risk getting sick using public transportation.

-- FMF_Family 26

Transportation to high quality daycare centers. I would like for him to be at a daycare that did a better job supporting his social emotional development but I had to go with one that offered transportation.

-- FMF_Family 3

Haven't had difficulty. Every time we need to get services, we were able to. We have always been able to get an interpreter and transportation wasn't an issue so we got everything we needed.

-- FSN_Interview 5

Among the many situation, one of them is that I have to travel an hour to receive services because the services are not provided in my area, because of the language barrier. I do not have my own transportation, and I have had to deal with Medicaid to provide transportation.

-- FSN_Interview 41_SP

The family survey also asked questions about the location of/getting to services, including the need for transportation and timing of services:

It is important to me that services I access for my child are close to my home

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	42.0%	15.4%	57.1%	43.6%	40.0%	46.9%
Agree	49.3%	61.5%	42.9%	53.8%	40.0%	42.9%
Disagree	3.6%	15.4%	0.0%	0.0%	0.0%	6.1%
Strongly Disagree	5.1%	7.7%	0.0%	2.6%	20.0%	4.1%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	44.0%	34.4%	73.3%	38.5%	50.0%	42.9%
Agree	48.0%	56.3%	26.7%	50.0%	40.0%	50.0%
Disagree	8.0%	0.0%	0.0%	3.8%	10.0%	0.0%
Strongly Disagree	0.0%	9.4%	0.0%	7.7%	0.0%	7.1%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

More than 90% agree or strongly agree:

- Race: Latinx respondents, both those responding in English and Spanish, felt most strongly about this. The one Hmong respondent said yes. Black respondents felt the least strongly at 77%.

- Income: Those just over the poverty line are the most interested in accessing services close to home. Others are all about the same.

- Gender: Male responses look similar to overall responses.

It is important to me that transportation is available for me to access services for my child

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	39.1%	38.5%	42.9%	43.6%	60.0%	26.5%
Agree	32.6%	38.5%	28.6%	43.6%	20.0%	24.5%
Disagree	21.0%	15.4%	28.6%	7.7%	20.0%	36.7%
Strongly Disagree	7.2%	7.7%	0.0%	5.1%	0.0%	12.2%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	44.0%	31.3%	60.0%	26.9%	40.0%	42.9%
Agree	32.0%	50.0%	26.7%	19.2%	10.0%	35.7%
Disagree	20.0%	12.5%	6.7%	42.3%	30.0%	14.3%
Strongly Disagree	4.0%	6.3%	6.7%	11.5%	20.0%	7.1%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

About 70% agree/strongly agree (40%/30%):

- Race: Most important for Spanish-speaking Latinx respondents (nearly 90%). White respondents aren't as focused on transportation as other respondents. The one Hmong respondent said yes.

- Income: Only around half of respondents over 150% FPL highlight transportation as important, while those with lower incomes are more focused on this (76% and 81%). Those just over the poverty line are the most focused on this (87%).

- Gender: Men rank this as very important (nearly 80%).

Barriers to Accessing Services: Transportation and Timing of Services

	I did not have transportation to take my child to or from these services?	The service was not provided at a time of day my child and I could go?	Number Surveyed
All	10.1%	13.0%	138
African-American/Black	0.0%	7.7%	13
Latinx (English)	7.1%	21.4%	14
Latinx (Spanish)	15.4%	5.1%	39
Native American	20.0%	20.0%	5
White	0.0%	16.3%	49
<50% FPL	4.0%	16.0%	25
50-100% FPL	18.8%	6.3%	32
100-150% FPL	26.7%	20.0%	15
150-200% FPL	0.0%	3.8%	26
>200% FPL	0.0%	50.0%	10
Male	14.3%	7.1%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Overall, these two issues did not rank highly among the 29 reasons for not accessing services that respondents were invited to react to. Thirteen percent had issues with the timing of services, and 10% had issues with transportation. However, transportation is a theme that came out again and again in the interviews.

- Race: Transportation was perhaps the biggest issue for Latinx (Spanish) respondents, 15% of whom noted it as a barrier. Two of the 14 Latinx (English) respondents marked timing as an issue, and only one marked transportation. One Native American respondent marked transportation, and one marked timing. These were not the main issues Black respondents were concerned with – none marked transportation and only one marked timing. White respondents were more focused on timing than transportation.

- Income: Transportation was mainly an issue for those right below and above the poverty line. Timing mattered most for those in the top income bracket.

- Gender: For men, transportation is more of an issue than for the overall sample, and timing is less of an issue.

Eligibility

Family voice on eligibility for services:

Better vetting system for who get services. I am working and raising children on my own and I can't get services (because I work) but people who don't work do.

-- PH_Interview 11

People shouldn't have to get kicked out at a certain time from a shelter. I think race has a lot to do with it.

-- FMF_Family 14

Services were hard to get. Services that were denied felt defeating after repeatedly applying and being denied over and over. Having to start over due to changes in criteria was frustrating. One thing that was good was that the psychological exam is good for the next 3 years and I can use it to apply for services. The inconsistencies of what was needed to be done to get necessary services was difficult.

-- FSN_Interview 17

You have to prove that the child has issues, and you want to scream that they can't do it without help. It seems you have to fail to get any support. I just had to speak out more, advocate more say just because I'm staying in a nice home doesn't mean I don't need help.

-- FSN_Interview 22

Threshold for issues impacting your needs make it so it's hard to get support if you don't have a "severe" issue.

-- FSN_Interview 24

lf [we] had not imploded, [we] would not have received help and services. You must be either loaded or butt broke to get help! There need to be services for the entire family because it affects everyone.

-- FSN_Interview 28

The family survey also asked about eligibility, referrals and waitlists being barriers to accessing services:

	I was overwhelmed by the amount of information I received when I shared my concerns with the doctor, teacher or other service provider?	I was told I or my child didn't qualify for some services, and I didn't know what I could do to get them?	My child received a service, but then I did not receive a follow up appointment or a referral for additional services?	I received a referral for a follow up or an additional service, but I was not able to or decided not to access it?	I received a referral for a follow up or an additional service, but the other program did not follow up with me?	I received a referral for a follow up but the times of day for that follow up did not work for me?	Number Surveyed
All	13.0%	10.1%	7.2%	2.2%	4.3%	6.5%	138
African American/Black	15.4%	7.7%	7.7%	0.0%	7.7%	7.7%	13
Latinx-English	14.3%	7.1%	0.0%	0.0%	0.0%	7.1%	14
Latinx-Spanish	7.7%	7.7%	7.7%	2.6%	5.1%	7.7%	39
Native American	0.0%	20.0%	0.0%	0.0%	0.0%	0.0%	5
White	18.4%	14.3%	10.2%	4.1%	4.1%	2.0%	49
<50% FPL	4.0%	4.0%	8.0%	0.0%	8.0%	8.0%	25
50-100% FPL	12.5%	3.1%	9.4%	0.0%	0.0%	6.3%	32
100-150% FPL	13.3%	13.3%	6.7%	6.7%	6.7%	6.7%	15
150-200% FPL	7.7%	15.4%	0.0%	3.8%	0.0%	3.8%	26
>200% FPL	30.0%	10.0%	0.0%	10.0%	0.0%	0.0%	10
Male	14.3%	14.3%	0.0%	7.1%	0.0%	0.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

The items noted by the most respondents include feeling overwhelmed by the amount of information provided (13%) and being told a child does not qualify for services (10%). Out of the four questions about referrals:

- Seven percent report not receiving a referral.
- Only three respondents received a referral but didn't end up accessing the service.
- Six respondents reported that they received a referral but no follow up.
- Seven percent received a referral but the scheduled day/time didn't work for them.

- Race: White respondents are most likely to report feeling overwhelmed by the amount of info (18%), followed closely by Black (15%) and Latinx (English) respondents (14%). One out of the five Native American respondents noted that they were told a child didn't qualify for services. White respondents reported that at about double respondents of other races/ethnicities, but due to small sample sizes, this may not be significant.

- Income: Very few people in each income bracket noted this an issue (only 1-3 people), which prevents useful analysis.

- Gender: Same as for income. Only 1-2 men noted these as issues.

Affordability

Family voice on affordability of services:

Sometimes they don't tell you the real cost of services. Believing they are free, and they are not. As a baby, he had a real good doctor, but there was an error with the insurance, and they were charging us a lot of money for the services for a whole year. Because of that we decided to leave, and I had to switch him.

-- CBP_Spanish Interview 5

Behavioral therapy, therapies are not easy to get due to income constraints. Income is a barrier. In order to get all necessary services, I would have to reduce my income to the point we couldn't live in our home. Because of income being too high to get services through a publicly paid program like Medicaid, to get the services he needs to the extent he needs, my income is too high for that. But I also don't make enough to pay for all of the services he needs and have a roof over our heads and shoes on our feet. I am away from him 60 hours a week at work and get up extremely early to be able to spend time in the evenings with him. I feel like I am always juggling everything.

They are missing the boat with middle income families. They need to find a way to emotionally support, provide some skills training and tools for all parents. Not make them feel that just because they don't have Medicaid, they don't get anything.

-- FSN_Interview 17

I feel like me having a job has been a barrier. Everything is income based. He was never eligible for SSI, Medicaid making services too expensive. My child still deserves services but can't get all services needed.

-- FSN_Interview 18

Not difficult to get services, but difficult to obtain affordable services.

-- FSN_Interview 23

If you do not qualify for Medic[aid] then must pay out of pocket for any services. Many middle-income families do not meet the financial criteria for assistance. Often you find a program, but you do not meet their criteria. You either must have Medic[aid] or are financially able to pay for treatment. Being middle-class makes it more difficult to receive treatment due to expense. There is no financial support. You are left to figure it out on your own. There need to be more centers and facilities available for the children who need help not based on financials.

-- FSN_Interview 24

Also going up in income was so hard because you lose so many supports and benefits even if your child has special needs. I feel like it's good because I'm moving up but support for the special needs hurt so much. Maybe there could have been a better transition or supports instead of just taking it all away when you make just a little too much and up getting nothing for the child's special needs.

-- FSN_Interview 7

The finances are all on me and it's hard to do more than work and care for my boys. With limited finances we can't access many programs because I work.

-- FSN Interview_30

We were getting ST and OT until we moved to NC and my husband's insurance changed and we can't afford therapy. He will [have] therapy now that school has started back. We don't qualify for Medicaid and the therapies are more than we can afford privately. I wish the cost of services didn't keep us from getting him the help he needs.

-- FSN Interview_35

The family survey also asked a question about whether affordability and insurance not paying for services were barriers to accessing services:

	I don't have the money to get these services?	My insurance won't pay for these services?	Number Surveyed
All	13.8%	12.3%	138
African American/Black	7.7%	7.7%	13
Latinx (English)	14.3%	14.3%	14
Latinx (Spanish)	12.8%	10.3%	39
Native American	0.0%	0.0%	5
White	20.4%	16.3%	49
<50% FPL	12.0%	0.0%	25
50-100% FPL	6.3%	3.1%	32
100-150% FPL	33.3%	40.0%	15
150-200% FPL	7.7%	11.5%	26
>200% FPL	30.0%	40.0%	10
Male	7.1%	14.3%	14

Note: The one Hmong respondent noted that Insurance and Money were issues for him/her.
Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Money (14%) and insurance (12%) were issues for some.

- Race: White respondents were more focused on insurance (16%) and money (20%) issues than respondents of other races/ethnicities. The one Hmong respondent noted that both the money and insurance were issues.

- Income: For those just over the poverty line and those in the highest income bracket (twice poverty), the concerns were mostly focused on insurance not covering the services (about 40% for both groups) or not having the money to pay for the services (around 30% for both groups). Some of those at 150%-200% of poverty were concerned about not being able to afford services (12%).

- Gender: For men, there was some concern about insurance not paying for the services (14%).

In discussing their difficulties in accessing services, respondents also talked about the importance of **family choice of services** and of services being **reliable** and **high-quality**, their frustration with their children being **labeled** (as opposed to diagnosed), their need for **respite**, not feeling comfortable **seeking help**, and their struggles with **additional pressures**, such as with **mental health, addiction, domestic violence, COVID-19, family economic security, and the justice system.**

It was interesting to note that many more families talked about *accessibility* of services being an issue than talked about *reliability* or *quality* being an issue. Accessibility, including awareness, availability, flexibility, eligibility and affordability of services, was a more pressing issue that quality and reliability of existing services.

Choice

The family survey asked a question about choice.

It is important for our family to be given choices about my child's services

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	68.4%	50.0%	85.7%	56.4%	60.0%	83.3%
Agree	27.2%	41.7%	14.3%	35.9%	40.0%	14.6%
Disagree	1.5%	0.0%	0.0%	2.6%	0.0%	2.1%
Strongly Disagree	2.9%	8.3%	0.0%	5.1%	0.0%	0.0%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	64.0%	65.6%	80.0%	69.2%	88.9%	64.3%
Agree	32.0%	28.1%	6.7%	30.8%	11.1%	28.6%
Disagree	4.0%	0.0%	6.7%	0.0%	0.0%	0.0%
Strongly Disagree	0.0%	6.3%	6.7%	0.0%	0.0%	7.1%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Choice is very important for families. This item received the second highest rating of any question on the survey, with 96% of respondents agreeing, and 68% of those 'strongly' agreeing.

- Race: Latinx respondents in English, white, and Native American respondents all or nearly all agree/strongly agree. 92% of Latinx respondents in Spanish and Black respondents agree.

- Income: Those at the upper end of the income spectrum (top two categories) all agreed, most of them 'strongly'. 96% of those in extreme poverty and 94% of those just under the poverty line agree. 87% of those just over the poverty line agree.

- Gender: 93% of male respondents agree.

Family voice on the need for choice:

It's important that we are given choices and my child is seen as an individual.

-- FSN_EngSurv2

Multiple providers to choose from.

-- FSN_EngSurv65

You cannot seek occupational therapies or speech therapies from anywhere else if your child is already receiving them through their school system. It limits their therapy.

-- FSN_EngSurv58

Reliability

Family voice on the need for services to be reliable:

Out of the resources I've had in the past, I'm not going to say it hasn't worked, but there's just a lot of inconsistency. We have a lot of transition, so we will get started then have to stop once it starts helping. She had a mentor through *** but it was just inconsistent. She had one for a month or two and then she got a new one. So that was really hard, because now she would [not] rather even deal with anybody or open up again. I just hate the turnover. We have seen so many caseworkers. Or things they do, they start then they don't finish. We have to start things over again. It's nothing against the workers… I have to retell my story over and over to three different people. I haven't seen good outcomes yet, because I go from social worker to different programs and it gets kind of agitating that we can't get things accomplished.

-- PH_Interview 10

She was going to refer us to Community Care of North Carolina. I talked to the nurse but she didn't do it. They never came to do the evaluation and when we talked to them the nurse said that everything was fine. Later they sent a letter saying that we were no longer going to receive the services, even though we had never received anything to begin with. I had to keep calling and searching [for] services for over a year. They didn't refer us.

-- CBP_Spanish Interview 6

Consistency is very important.

-- FMF_Family 1

I know it is hard for me to find a babysitter for when I need to go to work. My mom is the only person I could 100% depend on to watch him. She's my go-to person to depend upon when I'm at work. If I had a better support system or person for when I'm going to work.

-- FMF_Family 23

Quality

Family voice on the need for services to be high-quality:

I feel like you should have some type of evaluation on the people that are getting services from so the person who is helping with these things is being rated. Feedback is definitely needed.

-- FMF_Family 13

I sought a referral for treatment but was not comfortable with the providers. Did not choose to participate. I took it on myself.

-- FSN_Interview 24

As far as emotional support programs, some offer more support than others. Some are just there to receive the insurance money. Some really just want to help you.

-- FMF_Family 29

Also, the quality of care of the resources I was given. Since I work in the field, I was not comfortable going to some of the referrals I got.

-- FSN_Interview 26

Labeling

Family voice on concern with labeling:

Just with him being an African-American male, with the way he was acting I felt like he was automatically labeled and them wanting to put him in slow classes. Even I did that, I started second guessing myself and things I was doing.

-- PH_Interview 2

There are too many kids being labeled as troubled and that isn't the answer. They need to provide more services for parents to help get their kids backs on track.

-- PH_Interview 3

We never wanted him to be rejected. For us he is a normal child who has a different way of learning. We have kept his diagnosis a secret and only my mother knows, but she treats him normally as well. We also didn't want to talk to teachers about it at first.

-- CBP_Spanish Interview 2

They classify him (in school) as a rowdy, rambunctious child. He's just a curious child. If he sees Jimmy doing it, he follows suit. Don't classify him as being something he's not. Don't try to tell me he has some type of behavioral issue when that is not even the case. A lot of time they misdiagnose Black and brown children. There are discrepancies as far as that goes. Don't judge them as being bad kids. See what the issues are that kids could have. It could be a learning disorder, ADHD – try to figure out what is going on with them, their family life.

-- FMF_Family 30

Some people would say that Kindergartener was "bad". Maybe he needed a little more attention. Their environment impacted their behavior. People shouldn't label a child if you don't know them and their background.

I wished it wasn't so hard to get an accurate diagnosis, or especially to get a wrong diagnosis changed.

-- FSN_Interview 12_Foster

I wish we would have had more help from the preschool. He wasn't diagnosed then, and it was just that we knew he was difficult. But we could have gotten help sooner instead of just thinking he had bad behavior.

-- FSN_Interview 7

The family survey also asked a question about barriers to accessing services, including feeling embarrassed, fear of labeling, fear of feeling at fault, and fear of obligations or legal consequences that could result from accepting services.

	I felt embarrassed about using services that could support my child's social-emotional health and development?	I was afraid that if I shared my real concerns about my child's social-emotional needs that my child would be labeled?	I was afraid if I shared concerns about my child the provider would think my child's problems were my fault?	I was worried if I didn't agree with and do what the doctor or person providing my child's services told me to do I would get in trouble?	I was afraid to access the service because I was worried about legal consequ-ences?	I was worried about rules or obligations that they would want me to follow if I participated in the program?	Number Surveyed
All	3.6%	11.6%	11.6%	2.9%	4.3%	2.9%	138
African-American/ Black	15.4%	15.4%	30.8%	0.0%	15.4%	0.0%	13
Latinx (English)	0.0%	14.3%	0.0%	0.0%	0.0%	0.0%	14
Latinx (Spanish)	0.0%	2.6%	5.1%	2.6%	0.0%	0.0%	39
Native American	0.0%	20.0%	20.0%	0.0%	0.0%	0.0%	5
White	4.1%	14.3%	12.2%	6.1%	4.1%	6.1%	49
<50% FPL	4.0%	4.0%	24.0%	8.0%	8.0%	4.0%	25
50-100% FPL	0.0%	12.5%	9.4%	0.0%	3.1%	3.1%	32
100-150% FPL	0.0%	13.3%	6.7%	0.0%	0.0%	0.0%	15
150-200% FPL	7.7%	11.5%	7.7%	0.0%	7.7%	0.0%	26
>200% FPL	10.0%	40.0%	20.0%	10.0%	0.0%	0.0%	10
Male	7.1%	0.0%	0.0%	0.0%	7.1%	0.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Twelve percent fear it would be considered their fault and/or their children would be labeled. Other items are issues for just a handful of respondents out of the 138, including:

- Embarrassed: 5 respondents
- Worried would get in trouble: 4 respondents
- Legal consequences: 6 respondents
- Rules, obligations: 4 respondents

- Race: Among Black respondents, 31% report they are afraid the provider would think their child's problem is their fault. This is more than double the rate for the next highest group, white respondents (12%). One of the five Native American respondents also said yes to this item. About the same percentage of each racial group except for Latinx respondents in Spanish are worried that their children would be labeled.

- Income: Those in extreme poverty are mostly worried that providers would think their children's problems are their fault (24%). Those in the top income bracket agree. Fear of labeling roughly rises with income. Those in the bottom bracket aren't concerned about labeling (4%), those in the middle three brackets are slightly more concerned (low teens), and those the top income bracket are the most concerned with labeling (40%).

- Gender: Male respondents are not focused on these items, with only one of the 14 replying yes to embarrassment and one to concern about legal consequences.

Respite

Family voice on need for respite:

It would be good to have respite to do something for myself and not have mom guilt.

-- FSN_Interview 17

Respite care earlier on.

-- FSN_Interview 18

Respite care so I can have a break. Services in the home that come in and give non-judgmental help.

-- FSN_Interview 28

I need more respite to help him socialize more.

-- FSN Interview_31

Available daycare or respite.

-- FSN_Interview 42_Hmong

Comfort seeking help

Some respondents reported not being comfortable seeking help:

I am very reserved/shy and I almost never look for help. I try to solve things for myself before asking for help.

-- CBP_Spanish Interview 3

Being in a program made me more open to receiving help. It made me be more open to life and just knowing that I'm not the only one who is alone in it. Just talking to them and being that I relate with people a lot more than I thought I did.

-- FMF_Family 23

Just that it's okay to listen and to get help. This society, with my race, people think it is a problem if you need to get help. It's nothing wrong with you if you have a therapist.

-- FMF_Family 7

I just had to speak out more, advocate more say just because I'm staying in a nice home doesn't mean I don't need help.

-- FSN_Interview 22

Never ever asked for help with that, if they are here working with my son and I find myself feeling like that I find something to do with myself like mow the grass and do chores when his support is here. I never asked for help cause if they get my son doing what he needs to do I find that more gratifying then them taking their attention off of him to help me.

-- FSN_Interview 10

Additional pressures

Many family members shared their struggles with additional pressures, like their own mental health, addiction, domestic violence, COVID-19, and family economic security.

Mental Health:

They helped me identify that I had post-partum depression and explained that it would be okay if I showed symptoms. I was afraid that they would take the child. Since my husband traveled, I thought that they could take the child and when they asked me how I was I would say I was good even though I wasn't. It was ignorance because I didn't know how things worked, but we have false beliefs about how things work here.

-- CBP_Spanish Interview 2

Depression has made it difficult to follow through on things.

-- FMF_Family 27

I feel like child system is good, but I feel like there needs to be more support for mothers for [the] first month or two. There should be a mandatory postpartum meeting with a therapist to get things off your chest and understand how having a child has effects your life, just different topics. At least one meeting mandatory because you're still adjusting, and everyone processes things differently and I feel like if that were to happen than it would help you learn a lot and doctors could catch on to depression early on. Personally, I didn't want to have to talk to a doctor or therapist even though they offered it over and over. I didn't want to talk about my situation, but I don't have family around and if it were mandatory… at least one.

-- FSN_Interview 4

Addiction:

A lot of the girls here, we all struggle with addiction. We are all different, some of us have lost our kids in foster care, some kids were born addicted. My son has always been with me, even when I was using, some people don't understand that or are really harsh. A lot of people don't understand drug addiction. I love my child more than anything in this world, but this doesn't mean that I didn't still have struggles with addiction. There is a lot of taboo about motherhood and addiction.

-- PH_Interview 13

Domestic Violence:

More resources (housing resources, programs for women and children-parenting, programs for domestic violence). More resources for domestic violence survivors.

-- PH_Interview 14

COVID-19:

I wish they could do more in-home visits because they can't because of COVID.

-- PH_Interview 16

I don't think that we have much of a support system with the teachers at school and stuff with everything going on right now. I am not a teacher so it is really hard – I am teaching three grades!

-- PH_Interview 2

I think right now the schools are under so much stress because of what is happening. Having virtual learning is sometimes really stressful but other times its better. He can do things that he likes and then do the things he doesn't like.

-- PH_Interview 6

Going to school was the huge social and emotional challenge. He has really struggled with transitioning and moving from one activity to another. It was a lot of new people and things and schedules and it was a struggle. But this year because of COVID, he has a smaller class and its less stimulating and less overwhelming and more teacher attention and assistance because the class size is smaller.

-- FSN_Interview 7

Since COVID, he couldn't continue with the therapist.

-- CBP_Spanish Interview 2

I don't feel like I can take my child out there because no one else is wearing masks. I can't afford to miss work and get sick so I don't let her go out there and play with other kids.

-- FMF_Family 12

Before COVID-19, I was fine. He had classes and playdates. Now he doesn't have that.

-- FMF_Family 17

It is just difficult now with COVID19. It really, really, really messed up a lot. It is hard to do anything because people are losing their jobs and trying to support their kids. It's been rough, but I feel like people are trying. This is new on all of us. We definitely need mental health resources.

-- FMF_Family 30

COVID – not getting therapy in-person. Child did not do well with the therapist online, couldn't handle it. There was a negative change when tried to do it online.

-- FSN_Interview 25

COVID-19 has limited him from going to parks that he loves and helps him play and enjoy himself.

-- FSN Interview_31

The pediatrician she has now listens to my concerns and sets up evaluations and is reluctant to label her ADHD or anxiety since she is so young and has had some many changes in her environment with no school or gymnastics due to COVID-19. He wants to be sure that these changes are not the root of the situation but is ready to move forward as needed.

-- FSN Interview_32

Since he is non-verbal, his facial expressions, eye contact and hand motions help him share his feelings with people. He reads people's reactions by looking at them and is now confused a lot with so many people wearing masks. He tries to pull them off so he can see their face.

-- FSN Interview_33

The end of last school year and this new school year has been very difficult for him and us. We have not met his teacher, have no idea what she looks like, or his classroom or his classmates. He did not want to have school in a box. He wanted to go back to school with his teacher and friends. He does his work on a Chrome notebook and we are not technology savvy, so it has been a real challenge. He doesn't understand why we can't do things the way we used to.

-- FSN_Interview 34

He didn't want to go out because of Covid-19. Thanks to his EC teacher now we can go for walks and feel more relaxed. The teacher has provided supports and accommodations so that my son understood the situation of the coronavirus since he did not want to leave the house, this was stressful for me, the support that she offered was very helpful to me.

-- FSN_Interview 40_SP

She’s really socially shut-down. She rarely goes out. I think she’s afraid at this point to go outside because of COVID19 and the police. [Note: child is 9 years old]

-- FMF_Family 5

Family Economic Security:

More shelters, help with child support, food resources, clothing resources.

-- PH_Interview 11

If you are out of work, it should be easier to get Work First. Make it easier to access unemployment resources.

-- PH_Interview 14

City should pay to make sure no one is homeless.

-- FMF_Family 15

More jobs.

-- FMF_Family 20

Not having a stable place to stay has been a challenge for him.

-- FMF_Family 24

I feel like they should focus more too on the things people really need. It bothers me when people get more money for unemployment and essential workers like me are in the middle of it and they make more money in a week than I do in a month.

-- FMF_Family 4

The family survey also asked a question about whether respondents would use mental health services for themselves:

Would you use services for you if you need help with anxiety or depression?

	Would you use services for you if you need help with anxiety or depression?	Number Surveyed
All	42.0%	138
African-American/Black	46.2%	14
Latinx (English)	64.3%	13
Latinx (Spanish)	23.1%	14
Native American	80.0%	39
White	46.9%	5
<50% FPL	56.0%	49
50-100% FPL	37.5%	25
100-150% FPL	66.7%	32
150-200% FPL	26.9%	15
>200% FPL	60.0%	26
Male	28.6%	10

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Fewer than half of respondents said that they would use services to help with anxiety or depression. Therapy for parents and parent support groups were among the most common open-ended comments in the survey, however.

- Race: Latinx respondents in English (64%) and Native American respondents (4 out of the 5) are the most interested in these services. Latinx respondents in Spanish are the least likely to report that they would use these services (23%). Close to half of Black and white respondents report that they would use these services.

- Income: There is no discernible pattern among respondents by income, with more than half of respondents in the lowest, middle, and highest income brackets interested in these services, and less interest in the group just below the poverty line and the group just below twice poverty. The group most interested in these services are those just at and above the poverty line.

- Gender: Fewer than 1/3 of male respondents said they would use these services.

Are parents and caregivers experiencing racism in the social-emotional health system, and how do those experiences impact the receipt of services?

Respondents were asked about race and cultural competence of providers:

- *Have you ever felt like the way someone thought about your child was affected because they didn't understand your culture or background?*
- *Has race or the way people feel about race affected you and/or your child's experience in being identified as having trouble managing their feelings or getting along with others or in getting services to address a social-emotional challenge?*
- *How did that experience affect your engagement with those services? Did you continue using those services or participating in those programs?*

Respondents of all races reported incidents where they felt they had been treated differently because of their race. Many of the white respondents' comments were about incidents that happened with their biracial (usually Black and white) children, though some white respondents felt they were treated worse because they were white. Hispanic respondents reported incidents of linguistic insensitivity, while Black and white respondents did not. Many respondents shared examples of racially-based incidents that happened in the larger community (i.e., at the store, among family, in the neighborhood) rather than while accessing social-emotional health services. Finally, some respondents interpreted the word "culture" more broadly and shared examples of being alienated because of their children's disabilities, their socio-economic class, or being homeless or a foster family.

It is important to note that there were many factors at play during these interviews that may have prevented respondents from relating their experiences of racial bias in social-emotional health services, including:

- The social taboo in the US – and particularly the South – in talking about race or "playing the race card" may have prevented respondents of color from being comfortable relating their experiences. People also sometimes need a moment to think about whether they have experienced racial bias, given that they continuously hear the message that US society is "post-racial." This theory is reinforced by the number of respondents who initially replied "No" to the question, but then went on to relate an experience of racial bias. This internal tension/cognitive dissonance comes through in many of the respondents' comments (see below).
- In addition, respondents were being interviewed by staff members of the organizations that were currently providing them services (i.e., homeless shelter, preschool, etc.) and it is clear from some of the interviews that (though they were told otherwise) some of the respondents thought the interviews were to evaluate the quality of the services they were receiving from the organization that was interviewing them, rather than their

experiences of receiving social-emotional health services in general. Therefore, respondents of color (1) may have hesitated to share experiences of bias, not wanting to reflect badly on the organization that was providing them services, and (2) may have interpreted the question to be asking whether they had experienced bias in the services they were currently receiving from the organization interviewing them rather than in the ecosystem as a whole.

- Internalized racism (especially when layered onto internalized classism and the unavoidable power dynamics present in the interview situation) may have prevented some respondents of color from classifying negative experiences they have had as racially motivated.

Family voice from Black respondents on experience of racial bias:

Just with him being an African American male, with the way he was acting I felt like he was automatically labeled and them wanting to put him in slow classes. Even I did that. I started second guessing myself and things I was doing.

-- PH_Interview 2

Yes. I am an African American woman and there are a lot of things that are misunderstood about us and the way we raise our kids. We can't afford a lot of things for our kids, like clubs and stuff. Race is a big problem (…) Like the YMCA is so different in different neighborhoods. There are also different resources for different clubs depending on neighborhoods. My daughter did girls scouts and her troop didn't get the full uniform but other troops did. Kids notice that. (…) I want my child to participate in clubs with diversity. I try to keep my kids in things until the end but if it looks like they are at a disadvantage, we stop.

-- PH_Interview 3

I feel like they judge my child before they get to know him. Immediately assume he's a problem because of his race and where he is from. (I) have to do a lot of advocacy work to make sure he's not judged.

-- PH_Interview 9

I still believe that there is racism still going on. My child was suspended for having tantrums, but I don't think the daycare is racist.

-- FMF_Family 11

Yeah – because I don't want to put race into it. I see other kids do stuff. A little girl stabbed my daughter with a fork. I wonder if they are harassing other parents the way they are harassing me. The teacher gets frustrated if she doesn't take a nap. You got to have more patience. I hate to have to say that. We tried to meet about it with the director. Nothing is really helping. COVID-19 helped me because she only has one more class and then she will graduate (from elementary school).

-- FMF_Family 13

I think so. I feel like for us we don't have that many options or choice about or getting help. We have to show all this identification. By being different color skins we do get treated differently for getting help. Better programs get offered to non-Black kids. We have to ask and (white) people already know. You have to have so many documents.

Schools isolate the kids – segregate by race.

-- FMF_Family 18

Yes. I have actually had to step back from some people who said that my babies are bad. I know that they ask questions but I'm not just raising a child; I'm raising a young man who will need to be able to speak up for himself someday.

-- FMF_Family 28

I don't think it impacts my daughter as much but it impacts me. My name is "***meka" so I've been denied jobs because people automatically put me in a box. Her teacher who was Hispanic seemed to cater more to the Hispanic kids. This year her teacher is African and she calls me and emails me every day. Her teacher would do that last year for the Hispanic parents but not for my child.

-- FMF_Family 5

Yes, but not for the reason that you think. We are Black but we are educated proper. Sometimes I've felt a heightened level of being treated differently when trying to mix with the majority of my race. I know that (child) has experienced that. There were years when she would dumb herself down and downplay how smart she was because she knew she would be treated differently for being smart by her own race.

-- FMF_Family 6

Especially as a new person. Some people would say that Kindergartener was "bad." Maybe he needed a little more attention. Their environment impacted their behavior. People shouldn't label a child if you don't know them and their background. This society, with my race, people think it is a problem if you need to get help. It's nothing wrong with you if you have a therapist.

-- FMF_Family 7

Not towards me (Jamaican American), but sometimes I've noticed that a particular daycare may not work with a child in my care, so is known to be in foster care, and the daycare is less tolerant of their behaviors. I have expressed my concerns to the child's DSS social worker and we moved the child to a different daycare.

-- FSN_Interview 11_Foster

Family voice from Hispanic respondents on experience of racial bias:

I know there are support groups for families. I just wish there were more groups that fit my family. For example that have the same beliefs, same culture. It's harder to understand a person when you don't understand their struggles and culture.

-- FSN_Interview 1

When my daughter was in kindergarten, her teacher said they wanted to learn more about families who are from different countries. Last year she let me bring in a pinata around Christmas. In the school system more teachers need to do that.

I think it is very important because so many services in the community are based on …. Services seem to be stepping up for the Black community and Hispanic community.

-- PH_Interview 7

They helped me identify that I had post-partum depression and explained that it would be okay if I showed symptoms. I was afraid that they would take the child. Since my husband traveled, I thought that they could take the child, (so) when they asked me how I was I would say I was good even though I wasn't. It was ignorance because I didn't know how things worked, but we have false beliefs about how things work here.

-- CBP_Spanish Interview 2

In NY the daycares are in homes and where we lived there was a big community and there were Hispanic communities. Here it is different. There are a lot of children for only two care providers and it feels robotic. The person who cares for them doesn't have a connection and isn't very caring. They feel cold and I didn't want to leave my daughter in a place where the treatment was cold.

When one feels they are being treated well, with respect, you feel more comfortable and happier. I know that many people choose to leave programs that don't treat them well. Here in Charlotte, I see many parents who are worried and uncomfortable because of their immigration status or because the language and children are growing and they become insecure or anxious which is given to them by their parents and it affects how they see the future.

-- CBP_Spanish Interview 3

The pediatrician referred us to this clinic. There was someone who spoke Spanish at the front desk, but not anymore. The fact of having to find someone to translate for you, sometimes clinics don't have it.

-- CBP_Spanish Interview 4

At school, they delay everything because they assume he does not speak the language. They performed a second test to confirm he did speak the language. After all that, I left (the public school system), I wasn't able to keep him in the school I wanted to because (the school system) removed us from all the programs, including the lottery, he lost his spot. He did not adapt to the (school system) preschool.

-- CBP_Spanish Interview 5

Yes, of course. In places where you request services, they discriminate against you for the fact the you are Hispanic. Being able to speak English would have helped a lot. It is also different when you don't choose to leave your home country and come here. It wasn't an option. We had to leave from where we were and start from nothing. Life here is completely different. I worry that my daughter would not have these difficulties if we had stayed in our home country. We came here and have suffered discrimination and she hasn't been able to develop friendships.

We knew that services existed but they didn't want to give them to us. We had to keep trying and trying and pushing and pushing to even be able to access the services and get them to provide those services to us.

-- CBP_Spanish Interview 6

I don't know if it is just how I feel or if other people see me like this, but I feel that I can't request anything in this country. I feel like an intruder and I can't ask for anything and I think that limits me from receiving more benefits. However, my child was born here and is a citizen, so he has rights and I can ask for benefits for him. They have made us feel like health is a luxury that all of us can't acquire. In my country we couldn't have received any of this, and I tell other parents to fight for services and supports for their children. We all pay our taxes and when we do that we have rights, so we should make sure that our children benefit from what is available here.

At first, I felt like I didn't deserve benefits, but then my friend said it was a right of my child since he is a citizen and that made me think. And he is what I love most in the world, so why wouldn't I do everything possible to get more information and get more support for him. I had become committed to finding benefits for my children.

The therapist came that spoke Spanish and taught both of us, including me. I couldn't communicate with the coordinator. They were very nice people, but you couldn't communicate with them and it was hard because I was very interested in the services.

-- CBP_Spanish Interview 7

Hispanic culture has different beliefs and how we raise our children. I wish the services would help instead of judging.

-- FSN_Interview 3

The Speech therapist gave me some brochures but they were only in English.

-- FSN_Interview 40_SP

I already had three experiences where Medicaid providers and other providers that are supposed to take care of this kind of case has always denied the services, due to the language barrier and race… The opinion of a professional that my son did not need speech therapy because his delay was due to a confusion of language. My child was not treated by a pediatrician. Instead, he was assigned to a family doctor. Later, I learned that the pediatrician in my area does not care for a certain group of people of specific races, such as Hispanic, and the Medicaid provider assigned the Hispanic families to family doctors. Among the many situations, one of them is that I have to travel an hour to receive services because the services are not provided in my area, because of the language barrier. The Intensive Behavior Programs and programs related to the condition of my child in the county where I reside should be more sensitive to Spanish-speaking families.

-- FSN_Interview 41_SP

Family voice from Native, Asian, and respondents of more than one race on experience of racial bias:

People do look at us differently because we are a mixed couple and we have mixed kids. People do have a different outlook on that. Before he was born, there was a conflict with an acquaintance who said he was only Black and they didn't acknowledge that he is half Puerto Rican or that mom's heritage is Cherokee and Blackfoot Indian. I feel like his daycare treats him different because he is mixed. For example, his daycare would only talk to me (who is Black + indigenous) but not his dad (who is Puerto Rican).

If I was in a better situation, he would be at a better daycare. It would be a better outcome. I wish he were at a daycare that had a mix of different races, instead of only Black kids. I only chose that one because they offered transportation and this was the only option.

-- FMF_Family 3

We haven't had problems with services, just a few problems with the schools when he first started kindergarten, but those have improved.

-- FSN_Interview 36

I believe we were taken more seriously because we were highly educated and financially able. Everything moved smoothly and was easily accessible.

-- FSN_Interview 23

Black women's pain is overlooked because people think that they cannot feel pain.

-- FMF_Family 17

Family voice from white respondents on experience of racial bias:

My son is bi-racial, but he looks more white. He goes to a predominately African American school. I feel like there is a lot of racial inequality to him—most of his altercations have been with African American boys but he's always the one getting suspended. My niece and nephews go to the same school—their skin is darker. My sister-in-law went to pick all of them up and was questioned about how they could be related by the Principal. Feeling that the response was racist.

-- PH_Interview 1

I am white but I have mixed children, and one of my case workers treated me differently once she found out I had Black children. At first she was willing to help me find a house but when she found out my kids were mixed she wouldn't help me. She wouldn't help with paying the deposit for electricity. She stopped providing all the services that were available and I felt like I wasn't getting what I needed. I ended up having to figure everything out on my own.

-- PH_Interview 11

His dad is really Irish, and has some family that is also part Native American. They don't like to cut hair, because they believe that hair holds life. Here, people don't really understand that. I have never cut my son's hair even though he is three and a half years old, even though he doesn't look Native American. People are sometimes like "Cut that boy's hair because he looks like a little girl." I think that kids should be able to decide about their hair and expressing themselves.

-- PH_Interview 13

Yes, being judged by how he looks and assumed I was on drugs and that is why he is the way he is and that is not true and because of all of his medical needs and limitations so many people could not see what his abilities really are and wanted to limit his progress. As a single mom of a bi-racial child, sometimes people didn't think I knew what I was talking about and that I really knew my child. Race did not affect his services, his physical appearance and limitations have. We have declined preschool services since they don't want to challenge him and expect him to succeed and learn.

-- FSN_Interview 38

Right now it hasn't been a problem. But we have noticed that some kids with more visual disabilities like cerebral palsy in a wheelchair get more star treatment, more empathy, or more help than with my son with a more emotional mental disability. My son being Black is a concern for me in the future, because he is going to go from a cute Black kid to like he is Black and trouble. But it's his Autism. I'm preparing to be a strong advocate for my child, and I'm a very strong presence now at his school because I don't want him to get pushed around at his school. I don't want race to be a problem, but it frightens me that he has autism and is Black for the future. Especially with what is happening in the world with police. I train him to respect authority. We still go to school, but I advocate and teach him and make sure he isn't treated unfairly.

-- FSN_Interview 7

I believe race has a lot to do with everything. Everywhere you go it's all about color. The women and children's program that I am in people get treated differently based off race. I am continuing to participate but it is really hard cause I don't get treated fair or equal. The head director of the program she is a different color than me and when people of the same race do something it was a "mistake" but when people who aren't the same color do it they get in trouble.

-- PH_Interview 14

If I feel like I've experienced discrimination, I usually don't talk about it. Once we lived in an apartment complex and I felt like they were way harsher on us because we were the only white family.

-- FMF_Family 24

Not to my face, but I am certain that because of the way I conceived (single by choice, IVF), child's diagnosis and maternal age, I have been treated differently. I felt that it has happened but have had to let it go.

-- FSN_Interview 17

He is looked at as the poor, little white boy whose parents are really trying, they are more accepted outside their race. She believes that being a white family played into the delayed diagnosis. White folks trying to milk the system. While African American families could get all the services they needed. Grants and organizational funding highlight white groups as not desirable to be helped.

-- FSN_Interview 28

I get upset when people say I have "white privilege" and I tell them that services are available for all children of all colors. My being white does not change that. I continue to use the services that we have because no one from those services have made that comment.

-- FSN Interview_33

The family survey also asked about race and cultural and linguistic competency of providers and racism or language as a barrier to accessing services:

It is important to me that I receive services for my child from someone who speaks my first language.

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	50.7%	38.5%	50.0%	30.8%	60.0%	70.8%
Agree	39.0%	46.2%	35.7%	53.8%	40.0%	25.0%
Disagree	5.9%	7.7%	14.3%	10.3%	0.0%	2.1%
Strongly Disagree	4.4%	7.7%	0.0%	5.1%	0.0%	2.1%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	56.0%	41.9%	66.7%	46.2%	55.6%	35.7%
Agree	36.0%	41.9%	20.0%	46.2%	33.3%	50.0%
Disagree	8.0%	9.7%	6.7%	3.8%	11.1%	0.0%
Strongly Disagree	0.0%	6.5%	6.7%	3.8%	0.0%	14.3%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Ninety percent said that they agree/strongly agree:

- Race: All five Native American respondents agree/strongly agree, as do 95% of white respondents and about 85% of African American/Black and Latinx respondents (both those responding in Spanish and English). The one Hmong respondent said language is important.

- Gender: This seems to be slightly less critical for male respondents.

It is important to me that I receive services for my child from someone who is of the same race as my child and/or me.

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	5.8%	0.0%	21.4%	2.6%	20.0%	0.0%
Agree	9.4%	0.0%	7.1%	23.1%	0.0%	2.0%
Disagree	42.8%	61.5%	57.1%	59.0%	40.0%	22.4%
Strongly Disagree	42.0%	38.5%	14.3%	15.4%	40.0%	75.5%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	4.0%	9.4%	6.7%	3.8%	0.0%	7.1%
Agree	8.0%	9.4%	20.0%	7.7%	0.0%	14.3%
Disagree	40.0%	50.0%	33.3%	46.2%	50.0%	50.0%
Strongly Disagree	48.0%	31.3%	40.0%	42.3%	50.0%	28.6%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

This item received the lowest support of any item in the survey. Only 15% overall agree/ strongly agree:

- Race: The race of the provider was most important for Hispanic respondents, both those replying in English (28%) and those replying in Spanish (25%). Black and white respondents did not find the race of the provider important (0%, 2%). The one Hmong respondent and one of the five Native American respondents did find race important.

- Income: Those in the highest income bracket reported caring the least about the race of the provider, while those between 50%-100% of poverty (19%) and just over the poverty line (27%) cared the most.

- Gender: 21% of men, so slightly more important to them.

Barriers to Accessing Services: Language, Culture, Racism

	The services my child needs are not available in my first language?	I was not offered services that fit our family's culture or lifestyle?	Getting these services for my child is against my cultural or religious beliefs or values?	Racism and/or racial discrimination have prevented me from accessing these services my child needs?	Number Surveyed
All	6.5%	8.0%	0.7%	1.4%	138
African-American/ Black	0.0%	7.7%	0.0%	0.0%	13
Latinx (English)	21.4%	21.4%	7.1%	7.1%	14
Latinx (Spanish)	15.4%	10.3%	0.0%	0.0%	39
Native American	0.0%	0.0%	0.0%	0.0%	5
White	0.0%	6.1%	0.0%	0.0%	49
<50% FPL	0.0%	0.0%	0.0%	0.0%	25
50-100% FPL	9.4%	9.4%	0.0%	6.3%	32
100-150% FPL	33.3%	20.0%	6.7%	0.0%	15
150-200% FPL	0.0%	11.5%	0.0%	0.0%	26
>200% FPL	0.0%	10.0%	0.0%	0.0%	10
Male	7.1%	7.1%	7.1%	0.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

These barriers did not rise to the top among the 29 barriers to receiving services that respondents were invited to react to. Two respondents reported that racism is a barrier. One respondent reported that services were against religious or cultural values.

- Race: Latinx respondents in both English and Spanish reported that not having services in their first language is a barrier, and that services did not fit the family's culture or lifestyle.

- Income: Some respondents in the group just above the poverty line reported that language (33%) and cultural competence (20%) were relevant barriers for them

What experiences have families had with specific sectors of the system?

Respondents also shared their experiences with various sectors of the social-emotional health system, including:

- Perinatal supports
- Home visiting and other in-home supports
- Parenting education and community-based supports
- IDEA Part C/Early Intervention
- IDEA Part B/Exceptional Children
- Care management
- Medical home
- Health insurers
- Evidence-based programs
- Early education (child care, preschool and K-3 elementary school)
- Foster care
- Ecosystem supports

Perinatal Supports

I feel like child system is good but I feel like there needs to be more support for mothers for first month or two there should be a mandatory postpartum meeting with a therapist to get things off your chest and understand how having a child affects your life, just different topics. At least one meeting mandatory cause you're still adjusting, and everyone processes things differently and I feel like if that were to happen than it would help you learn a lot and doctors could catch on to depression early on. Personally, I didn't want to have to talk to a doctor or therapist even though they offered it over and over I didn't want to talk about my situation but I don't have family around but if it were mandatory at least one.

-- FSN_Interview 4 --

The NICU was often mentioned when respondents were asked to tell about a time they felt welcomed, understood, or valued by someone who helped their family.

Education in NICU was helpful. She learned what to expect. She was prepared when her son exhibited the things they talked about. She would have liked treatment herself, so she could process things that her son needed.

-- FSN_Interview 21

Wish I knew earlier about CDSA. At 9 weeks baby was in hospital but no one told her about CDSA.

-- FSN_Interview 23

Someone reached out to us a couple days after my son was in the NICU and called like 2 or 3 different services and they even came and saw us in the NICU. That was good because we had so much to call and follow up on and deal with the kids at home it was nice to have some of that already taken care of.

-- FSN_Interview 2

Actually going to P2P meetings and NICU playgroup and seeing different moms how they dealt with their kids in certain situations helped me a lot. My kids were still really little and (the other parents) were really calm and they were really good at it and I was still trying to learn. So just watching other moms in support groups deal with kids was really helpful. Just being around them really helped me with my emotional stress and my depressional stress I was going through and it really helped a lot.

-- FSN_Interview 4

My experience was very good. Everyone at the hospital was very helpful. I didn't have any problems getting the resources I needed to get for him. The nurses were outstanding, I would have to leave and I knew he was in good hands.

-- FSN_Interview 6

Black women's pain is overlooked because people think that they cannot feel pain. When I was giving birth, I had requested a specific doctor. She rushed to me when I had to have an emergency c-section and I was very grateful. She made me a priority; I didn't want to go through that with anyone else. I had a breakdown on the second day after giving birth. The nurse made me feel better when I was upset.

More doulas. Make home birth not as unwelcoming. More education about natural childbirth. Keep away from extra drugs into you and the baby.

-- FMF_Family 17

Home Visiting and Other In-Home Supports

Respondents noted home visiting as a service they wished there were more of:

High quality daycare, home visitor.

-- FMF_Family 10

I wish there were more Intensive In-Home Service programs available for young children birth – 3yrs old.

-- FSN_Interview 15

They could do more in-home visits, but they can't because of COVID.

-- PH_Interview 16

I would like my kids to have the Home Skill service, but because he doesn't have a waiver, he cannot have it.

-- FSN_Interview 40_SP

Q: What would a good partnership between you and your child's doctor, teacher, or support person look like and feel like?
A: It would look like I have their number saved in my phone and I know I could call them anytime and someone would come to my home to check it out.

-- FMF_Family 21

They discussed how home visiting was helpful:

My daughter was born in Oklahoma and we lived there for the first four years. We did a home visitation program, that worked really well. When I was in the home visitation program, being able to speak Spanish to other parents was really helpful.

-- PH_Interview 7

Every one of those offices that we had to sit in was such a demeaning experience. This was such a different experience. My CDSA coordinator came to my home.

-- FMF_Family 6

We've had many children where Intensive In-Home Services were provided so they had a team to help the child calm down and support them, along with services from the Mobile Crisis Unit provided.

-- FSN_Interview 12_Foster

When my daughter was not verbal, doctor recommended services to be helped at home. It has helped, and gave ideas to assist my child.

-- FSN_Interview 42_Hmong

Q: Who or what has helped your child or children learn how to make themselves feel better when they are upset, scared or sad?
A: The services (MH therapy & Intensive In-Home Services IIHS) that have been in place.

-- FSN_Interview 14_Foster

Early Intervention was helpful. They made a home visit and saw that the house was in disarray. She offered to help her get it picked up and organized. (I need) Respite Care so I can have a break. Services in the home that come in and give non-judgmental help.

-- FSN_Interview 28

They discussed their frustrations with home visiting:

Home care nursing is very unreliable—organization is not done very well—nurse will get scheduled and then there is no back up if they end up not being able to come.

-- PH_Interview 1

Child was participating in Early Head Start home visiting program and family liked it, but home visitor was not available in the evenings once child started attending daycare.

-- FMF_Family 1

The family survey also asked some questions about home visiting:

It is important to me that services for my child are provided in my home or where I live

	All	African American/Black	Latinx (English)	Latinx (Spanish)	Native American	White
Strongly Agree	19.7%	0.0%	42.9%	23.1%	20.0%	8.3%
Agree	53.3%	69.2%	28.6%	59.0%	20.0%	58.3%
Disagree	21.2%	23.1%	28.6%	15.4%	40.0%	25.0%
Strongly Disagree	5.8%	7.7%	0.0%	2.6%	20.0%	8.3%
n	138	13	14	39	5	49

	<50% FPL	50-100% FPL	100-150% FPL	150-200% FPL	>200% FPL	Male
Strongly Agree	12.0%	18.8%	40.0%	7.7%	0.0%	28.6%
Agree	56.0%	50.0%	53.3%	57.7%	77.8%	50.0%
Disagree	24.0%	21.9%	6.7%	30.8%	11.1%	7.1%
Strongly Disagree	8.0%	9.4%	0.0%	3.8%	11.1%	14.3%
n	25	32	15	26	10	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Seventy-three percent agree or strongly agree, but only 20% of them strongly:

- Race: Lots of variance based on race/ethnicity. Latinx respondents – both those responding in Spanish and English – are more interested in services in the home than respondents of other race/ethnicities. Spanish-speaking Latinx respondents are most interested in this (82%). Black and white respondents fall in the middle. Native Americans are less interested than other respondents (2 of the 5 respondents). The one Hmong respondent said yes.

- Income: Those just over the poverty line are the most interested. Others are all about the same, with those in the top bracket not "strongly" agreeing.

- Gender: Male responses look similar to overall responses.

The survey asked whether respondents would like to access services through a home visit (versus other ways of getting information, like through a parenting class, online, or through an app).

How do you like to access services?

	Would you use someone to visit you and provide information?	Number Surveyed
All	58.0%	138
African American/Black	46.2%	13
Latinx-English	50.0%	14
Latinx-Spanish	56.4%	39
Native American	40.0%	5
White	71.4%	49
<50% FPL	64.0%	25
50-100% FPL	56.3%	32
100-150% FPL	73.3%	15
150-200% FPL	50.0%	26
>200% FPL	60.0%	10
Male	50.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

More than half of respondents would use a home visit (58%):

- Race: White respondents are more interested in a home visit than others.
- Income: There is no particular pattern by income.
- Gender: About half of male respondents would use a home visit.

Family voice on home visiting:

Someone that comes and sees my child's struggles in their natural environment.

-- FSN_EngSurv19 --

In-home teaching services that would help me learn to maintain a schedule and accommodate my child's needs.

-- FSN_EngSurv52 --

That they visit us at least once a month in our home.

-- FSN_SpSurv6 --

The survey also asked respondents to share where they would use services:

	Would you use services at your child's school or child care?	Would you use services through your child's doctor?	Would you use services at your home or where you live?	Number Surveyed
All	60.9%	33.3%	78.3%	138
African-American/Black	61.5%	30.8%	53.8%	13
Latinx (English)	78.6%	50.0%	85.7%	14
Latinx (Spanish)	64.1%	20.5%	79.5%	39
Native American	80.0%	80.0%	60.0%	5
White	53.1%	36.7%	79.6%	49
<50% FPL	52.0%	60.0%	64.0%	25
50-100% FPL	56.3%	28.1%	87.5%	32
100-150% FPL	66.7%	33.3%	86.7%	15
150-200% FPL	57.7%	19.2%	80.8%	26
>200% FPL	80.0%	30.0%	80.0%	10
Male	57.1%	21.4%	71.4%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

The highest number would like services at home (78%). More than half would use services at school/child care (61%), and respondents are less interested in services through a doctor (about one-third).

- Race: Hispanic and white respondents are very interested in services at home; Native American and Black respondents less so, but still more than half. Black respondents are most interested in services at school, then home, then doctor. Hispanic (both) and white respondents are most interested in services at home, then school, then doctor. Native American respondents are interested in school and doctor, then home.

- Income: More than 80% of every income bracket, except those in extreme poverty, are interested in home visits.

- Gender: Male responses are similar to the overall responses.

Parenting Education and Community-Based Supports

When asked what services and programs they wish were available to support their children's social-emotional health and development, the most common thing mentioned by parents are community programs for children – places they can learn and play safely. Hispanic parents are also very interested in more information about how the systems work and how to access community and other programs for their children.

Black and Hispanic parents are also very interested in programs that build their children's social skills by interacting with other kids, and in support groups. White parents are slightly less interested in social skill-building and are not very interested in support groups.

<u>Family voice on knowledge of child development:</u>

I wish I knew early on what to do or what to look for.

-- PH_Interview 10

It is important to understand that sometimes a parent can't do it themselves or don't have understanding about a given topic.

-- CBP_Spanish Interview 1

You don't know if you are doing things right or wrong and you don't know if his reactions are because something was happening or because you are failing as a mother to raise him. It would have been good to know that these things happen. It would have saved me some frustration and I could have kept him from that.

Focus more on educating parents, to give them greater awareness and knowledge of the supports and the system. The hospital gives you a book and tells you how to manage things day-to-day but they don't guide you or talk to you about how the system works. You have to choose a pediatrician alone, no one helps you. You aren't born knowing all of these things and knowing how to be a parent. You also have these barriers in the system that aren't clear. You don't know what resources exist, when you can receive them or when your children can receive them.

-- CBP_Spanish Interview 2

It should start with the pediatrician. It starts when they are tiny babies. They should tell you they need to interact with other children. When he was born, I didn't know any of that. We think that protecting them and keeping them at home is a good thing and you don't realize it's harmful, I wish I had been more laid back. When I worked, I left him with a family member. If I had informed myself, I would had taken him to a daycare or taken him to programs in churches and I didn't due to fear of what could happen since I wasn't there to watch. To turn him loose would had made a huge difference. There is a lack of clear information. They assume we have the same knowledge about how to involve the child with the society.

-- CBP_Spanish Interview 5

Someone who teaches us how to manage the unique challenges and personality of children. It would be good to have more advice and guidance. We know a lot as parents but we want to learn more.

-- CBP_Spanish Interview 8

No one actually sat down with me and talked with me about how to care for a baby.

-- FMF_Family 2

The Early Intervention program experience in PA was very helpful to help me understand early development for children.

-- FSN_Interview 15

She wished she knew the definition of socio-emotional development when her daughter was younger and knew how to help her more. Would like this to have been explained to her when she was diagnosed.

-- FSN_Interview 23

More available information about parenting.

-- FSN_Interview 24

He is learning to sign some but we don't know enough signs to communicate with him like we would like too.

-- FSN Interview_35

Family voice on community programs for young children:

Programs like YMCAs, Boys and Girls Clubs, sports programs, afterschool programs, Big Brother/Big Sister, and mentoring programs were mentioned a lot. Many respondents mentioned that these types of programs were available to them when they were growing up and that they are no longer available for their children. Many respondents noted that these community activities need to be free and available nearby.

Other things family members mentioned include:

I wish there were more small group activities for them. Some of the camps were full during the summer. More kid-friendly activities in general. Community Centers would be a good hub.

-- FMF_Family 26

After School Programs: We have trouble affording them. Boys and Girls Club, Tutors, Sports clubs, and Teen Activity Clubs. The school provides some things but would like more places for 3 and 4 years old where they can interact. We use the library but I wish there were more activity places like a big Chuck-E-Cheese. Places for learning and mental development.

-- PH_Interview 3

More child places—more child's activities; playgrounds, play places, places for them to unwind—museums, zoos-public places.

-- PH_Interview 4

More programs he can participate in that include our entire family, like movie nights or picnics or community events. I wish there were sibling programs to help his brother also and that services would be more local and cost would not prohibit our participation in them. We need opportunities to be with other families going through lots of things we are going through.

-- FSN Interview_31

There are a lot of things that I had when I was growing up. It wasn't like it is today. Before, I could go to a community center from a young age. Please more young age activities – more of that. They have a lot of teen centers and stuff but it is important to have more centers and space for the younger kids. Do it for the kids that don't cost.

I want more mindful activities. Their brains are like sponges so let's fill it up. More young-age activities (not even school-aged) activities that teach kids about money and helping kids think about how to start your own business.

-- FMF_Family 4

Things like iCan Swim, iCan Bike, Dance, therapies like speech and things through the CDSA more accessible for working families. Respite care earlier on.

-- FSN_Interview 18

Community and church programs and extracurricular programs that are easy to access and that Medicaid will approve of.

-- FSN Interview_33

There need to be more centers and facilities available for the children who need help not based on financials.

-- FSN_Interview 24

She would like fenced in playgrounds with equipment suited to special needs children. Feels fencing would be good at playgrounds to provide peace of mind for all parents.

-- FSN_Interview 28

Family voice on programs that specifically support young children's social skills:

Only thing I can think of is if there was a program that was more centered on getting kids together to practice their social skills. I have been a stay-at-home mom with him and don't have any other kids, don't have a car, lived in the middle of nowhere. When I got here, it was really hard because he didn't know how to interact with other kids. So maybe a program where kids can practice those social skills for kids who don't have that social skills. The only way to help them get better is to expose them.

-- PH_Interview 13

I wish I could get her into that type of setting where she could just learn to listen to other people and play with other people without it being daycare. She needs to learn how to share and things of that sort. I did sign up for Smart Start but there is a waiting list. Wish there was just something else besides daycare because we can't afford that, but I want her more social. I wish I could get her playing with other kids before she had to enter school.

-- FSN_Interview 2

The one-on-one programs for kids who have trouble finding friends.

-- PH_Interview 8

A program to help young children learn how to interact with one another. It makes me nostalgic to see him get frustrated with being here in the house, closed off. It would have been good to have more knowledge, more support. Like a program that could help children learn to interact with other people.

-- CBP_Spanish Interview 1

I wish in North Carolina there were more programs to provide 1:1 work with young children and social skills peer play groups like my older child received in PA.

-- FSN_Interview 15

A social group for kids on the spectrum and even my 5-year-old. An interactive program like structured playtime where kids and parents can go. A program that would work on social skill building in a social setting with other kids about their age.

-- FSN_Interview 20

Play groups that are her age level and local so we didn't have to travel too far to come let her being with other children her age with ADHD and anxiety. She was a preemie and she has lots of sensory issues.

-- FSN Interview_32

Family voice on support groups for parents and/or children:

Groups for parents to talk together. Like support groups but they NEED childcare. We miss out if we can't bring our kids. You can't get stress relief if you have to watch your kids at groups or you just miss out completely.

-- PH_Interview 3

A more robust support group in the community, a larger network, parent-to-parent, counselors for parents with special needs family member. Didn't find out about FSN till a few months ago. It would be good if other services knew about it and gave out information.

-- FSN_Interview 23

I know there are support groups for families, I just wish there were more groups that fit my family. For example that have the same beliefs, same culture. It's harder to understand a person when you don't understand their struggles and culture.

-- FSN_Interview 1

Single parent programs (us single parents supporting each other – support groups).

-- FMF_Family 9

Just more support groups for moms and more playgroups where kids can learn and play together. Even before COVID we would just stay home all week. so it would be helpful to have more meetings to hang out with moms and discuss our stories and what we go through and kids have snacks and play together.

-- FSN_Interview 4

We need more support groups for children her age with anxiety and ADHD tendencies. Virtual learning is not working for her and she wants to go back to school and be with her friends and her teacher.

-- FSN Interview_32

The family survey included a section for open-ended responses. Twenty-six respondents commented in that section that they wanted parent support groups – more than any other single type of comment:

Peer support, group settings and meeting with other parents with a professional guiding and leading.

-- FSN_EngSurv68

To have talks or a class to talk about the theme and how we feel and identify with the other families.

-- CBP_SP34

Talking to other parents who have experienced these concerns.

-- FSN_EngSurv17

Access to local child psychologist and active parent support groups.

-- FSN_EngSurv27

Parent forums to share experiences and ideas.

-- FSN_EngSurv54

To share/to talk with other parents who are raising young children.

-- CBP_SP10

A relief/support group with other moms.

-- CBP_SP12

The family survey asked a question about whether respondents would use a parenting class (versus other ways of getting information, like through a home visit, online, or through an app).

How do you like to access services?

	Would you use a parenting class?	Number Surveyed
All	51.4%	138
African American/Black	38.5%	13
Latinx-English	50.0%	14
Latinx-Spanish	64.1%	39
Native American	20.0%	5
White	57.1%	49
<50% FPL	48.0%	25
50-100% FPL	50.0%	32
100-150% FPL	60.0%	15
150-200% FPL	53.8%	26
>200% FPL	70.0%	10
Male	35.7%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

About half of respondents said they would use a parenting class.

- Race: At least half of Latinx-Spanish (64%), white (57%), and Latinx-English (50%) respondents are interested in a parenting class. Black (38%) respondents and Native American (1 respondent) are less interested in a parenting class than others.

- Income: In general, the higher the income, the more interested respondents were in a parenting class.

- Gender: Only about a third of male respondents would use a parenting class.

Family voice on parenting classes:

Parenting support groups, Educational opportunities to learn about what to expect.

-- FSN_EngSurv47

I feel as I would benefit the most from a class but with covid precautions an online class or app would also be beneficial.

-- FSN_EngSurv66

I would love to hear about parenting classes.

-- PH_3

Early Intervention, IDEA Part C

Early Intervention was often mentioned when respondents were asked who helped them learn how to support their child's social-emotional development or to discuss a time they felt supported:

All of the people involved in his development. The speech therapist, occupational therapist, Growing Together, everyone has contributed to his exploration of new environments – both outside of the house and with other children. We started the program because the therapist referred us because he stopped talking. In that moment the sent us to a program with the county for kids under 3 years old where they identified the services he needed. That was when my second child was born. With the first I had post-partum depression and they gave me the support of a family psychologist who visited me and did the evaluation. They identified the needs that we had. When he turned 3 they referred us to Charlotte Bilingual Preschool.

-- CBP_Spanish Interview 2

Dealing with King's care and medical team. His early intervention team. His pediatrician and his early education coordinator from CDSA were overwhelmingly warm and comforting and resourceful and we didn't even really know how much help we needed. We needed help and we got what was needed and not in a demeaning manner. We didn't have to go to DSS and sit with a bunch of people with crappy attitudes. We had to rely on resources until each of them were 5. Every one of those offices that we had to sit in was such a demeaning experience. This was such a different experience. My CDSA coordinator came to my home.

-- FMF_Family 6

Q: Who or what has helped you as a parent or family member learn how to support your child's social-emotional health?
A: Probably CDSA. Our OT, she was our son's best friend and my best friend so she helped support us a lot.

-- FSN_Interview 8

We've only dealt with CDSA and Child First which were positive experiences for the most part.

-- FSN_Interview 13_Foster

CDSA was a good experience, they helped in the process of transitioning to school. Preschool transition coordinator. CDSA to school. She heard me and understood what I was going through and was very supportive.

-- FSN_Interview 22

The Early Intervention Program and the CDC has helped significantly. Our first foster-adopted son, diagnosed with Autism, was enrolled in the Child Development Center (CDC) and that proved to be a good experience overall for his social-emotional development. He was non-verbal for much of his early years.

-- FSN_Interview 16_Foster

CDSA and speech therapy were services we used. At 2 ½, CDSA did an evaluation. They were easy to talk with and genuinely nice to work with. We worked with 3 professionals, OT, Speech and PT. They were flexible, did not get upset with a non-cooperative boy. They gave us a clear answer.

-- FSN_Interview 24

Early Intervention was helpful. They made a home visit and saw that the house was in disarray. She offered to help her get it picked up and organized. She explained to the children that they needed to help their mother with chores.

-- FSN_Interview 28

My service coordinator at the CDSA, Walkin'Roll, Ainsley's Angels and other support groups help me feel welcome and helps to give us a break between doctor appointments.

-- FSN_Interview 36

Certain services were easy like Early Intervention services and others were like pulling teeth. My service coordinator and therapists when he was in Early Intervention helped us so much, made us feel welcome, and valued my opinion, my pediatrician and some of my nurse.

-- FSN_Interview 38

A Case Coordinator at CDSA accompanied them for her daughter's evaluation. She was kind, supportive, encouraging. Told them to call anytime they had questions or needed help. Told them there was hope and not to lose hope.

-- FSN_Interview 23

Talking to therapists about what is "normal " for a premature baby and what is to be expected due to their drug exposure from the beginning and what might be long lasting effects. Just talking it out and knowing what's best is important.

-- FSN_Interview 37

When asked if someone helped them identify their child's need, some respondents talked about Early Intervention:

It was in the clinic. In March he turned two years old and I took him. For me, it was normal that he said 5 or 10 words, but in the clinic, they told me that he needed to be able to say more words and they gave me a therapist. They called me later, it was fast, and asked for more information about the child and then they did an exam to whether or not he needed therapy and they saw that his progress was very slow. He understands what is said but he doesn't say everything. The day of the exam they told me that he needed therapy and later sent options and schedules, and I chose the one that spoke Spanish. A week and a half later the services started. I imagined the therapy differently, more than anything like a teacher. Since it was my first time, I didn't know how it would be.

-- CBP_Spanish Interview 1

I went to the pediatrician, but I was already investigating and found something about autism online and took it to the doctor. She sent us to the therapies. I told them that I had read and that he was showing many symptoms. They sent us to a developmental expert who detected autism.

-- CBP_Spanish Interview 2

When I told the pediatrician that I needed a specialist, she referred me to a place. They did a hearing exam, a vision exam, and a speech exam. It was because the pediatrician sent me.

-- CBP_Spanish Interview 7

Through my own observations or as related to me by the daycare workers or teachers, or when tested by CDSA and then hear of notable deficits/needs.

-- FSN_Interview 11_Foster

Our local CDSA assessed the sibling pair and got services through Child First in place.

-- FSN_Interview 13_Foster

The CDSA who completed the assessment/evals with my children helped me better understand their speech delays and special needs.

-- FSN_Interview 15

It is not normal for a child to attack another person for no reason, and for this I need behavioral therapies, so that he can learn to manage his emotions. Talking with people about these behaviors, I learned that it is not a stage, and it has been useful because I could notice that the behaviors are not part of the terrible twos stage. They are not normal, and it is not that I am educating him in a wrong way.

-- FSN_Interview 41_SP

When my daughter was not verbal, doctor recommended services to be helped at home. It has helped, and gave ideas to assist my child.

-- FSN_Interview 42_Hmong

Insufficient resources for young children/late identification:

Initially her pediatrician told her not to worry about it. At another visit when it was discussed the doctor referred her to CDSA. Mom would have liked a referral sooner.

-- FSN_Interview 27

I just wish I could have gotten him into a place and he would get help while he was younger. I just wish there were more resources for younger kids. There are no resources for kids his age. He is 2.

-- PH_Interview 14

I wish there were more services/programs to work one-on-one like I had in PA for children birth-3yrs.

-- FSN_Interview 15

I wish there were counseling services for children his age. I've heard there are some available for older children. My son has been through a lot of challenges that I don't think I will able to help because of his condition.

-- FSN_Interview 6

I just wish we could have identified his needs sooner and got support when he was younger. [Need] more education to families about how to find resources as soon as possible after their child is born if they have concerns and to get them evaluated early to put the resources in place so that their child can be more successful and have less social-emotional issues before they reach kindergarten.

-- FSN Interview_31

I signed up for WIC and child support services. When my son was young, I feel like there could have been someone early on at that time to do testing with him. We didn't get a diagnosis until he was 5, but I was on WIC and all kinds of support so I feel like the welfare program could have been used as an evaluation time, like actually evaluate the kid. It's more about 'oh here is your check,' but no real care about making sure your kid is where they need to be. It's like they want to make sure they're fed but they don't care if, you know, if the kid falls through the cracks. I don't know how early intervention could have helped with that, but I'm thinking that if you're getting support from social services, they could help more – give us more information and communication about services so we don't fall through the cracks.

-- FSN_Interview 7

We wish she could qualify for ABA since she is waiting on being tested at the *** Center and the waiting list to be evaluated is so long. She didn't receive her early atypical diagnosis until after she turned 3 and it is easier if she had been diagnosed before she turned 3… Being diagnosed earlier and not feeling like it was just a "twin" situation.

We need ABA services now and wish we could have had a earlier diagnosis. We were concerned about which therapists were the best for her situation. CDSA was very helpful, Pre-K, Buster the Bus and private therapy. I would change how long the wait time is for evaluations. Just knowing what to do when we knew things were different but didn't want to make mistakes just because she was a twin.

-- FSN_Interview 39

I liked CDSA. They were very friendly, easy to use, easy access, came to the house. If you couldn't afford treatment, insurance proved to be very expensive. Wish I knew earlier about CDSA. At 9 weeks baby was in hospital but no one told her about CDSA.

-- FSN_Interview 23

Issues with Timelines, Accessibility, Affordability, Eligibility in Early Intervention:

Providers should care for a child with Medicaid immediately (when) they receive a referral. While time goes on, the progress of the child gets delay(ed) and will be more difficult later.

-- FSN_Interview 41_SP

The CDSA after assessing my child's speech delays did seem slow to get the needed services in place.

-- FSN_Interview 15

The inconsistencies of what was needed to be done to get necessary services was difficult. I would like to have had things move along quicker.

-- FSN_Interview 17

Things like iCan Swim, iCan Bike, Dance, therapies like speech and things through the CDSA more accessible for working families.

-- FSN_Interview 18

CDSA was harder to navigate through the system then she thought it should. Took way too long to get services. Finally she gave up because she felt time was slipping away. She did her own research and found her own therapist. There are not very many therapists in the area so she had to drive to a neighboring county. It was difficult to go 4 times a week while having a job and other responsibilities.

-- FSN_Interview 21

CDSA was not helpful and they were mediocre with therapies. It was cheaper for me to direct pay for therapies through my insurance than to use their sliding-fee scale. They told me that I couldn't check out things like 'Signing Times" videos because my child didn't have Medicaid. Services were hard to get. Services that were denied felt defeating after repeatedly applying and being denied over and over. Having to start over due to changes in criteria was frustrating. They are missing the boat with middle income families. They need to find a way to emotionally support, provide some skills training and tools for all parents. Not make them feel that just because they don't have Medicaid, they don't get anything. Need to better train Case Workers.

-- FSN_Interview 17

Issues with aging out/transitions:

We lost a lot of support once he aged out of Early Intervention Services and had to coordinate a lot of things on our own without knowing how. CDSA staff and therapists were very helpful and we need support when we age out of their services, not just school services.

Be more understanding of parents and not as judgmental and provide more support services even when the child ages out of CDSA services. Provide support and equipment without so much red tape and respect the family.

-- FSN_Interview 38

When Early Intervention came out to work with my son, I really wish they could have worked with him until at least 5, that would be really helpful.

-- FSN_Interview 10

When I started working with the county, I felt supported. That was a connection, and they understood my situation. There were trained people and I knew I was in the right place. The person who carried out the process was very attentive to me and my child and I felt good. They were available. Once he turned 3, they couldn't help anymore, which seemed unbelievable that after so much work they would just leave us alone. The child was small and we didn't know what to do. I felt afraid without knowing how to do everything because the coordinator was the one who organized everything, made phone calls and made me feel taken care of.

-- CBP_Spanish Interview 2

Other Frustrations with Early Intervention:

Our story is a little different. We went to CDSA from DSS. My son had a fracture, and they put him in foster care and they put him in CDSA because he was premature. As far as our situation, what I wish would have been different, the CDSA workers that were coming out were like 'well if he wasn't fractured this wouldn't have happened' or 'if he wasn't fractured he would have the leg strength to stand up,' and I had to go through loopholes to prove that wrong. I just wish it would have come out that it wasn't an abuse situation, it was a complete and utter accident, so I guess the whole time I felt like the case worker was not understanding or making assumptions. Up until last year his case worker called my kids' dad 'the abuser'. It took me finally saying 'he did not abuse our children, do not say that anymore'.

Also the constant change in therapies makes it hard to get anything done. By the time he starts getting use to a therapist and making progress they change and we have to start all over. Its hard to be in a grove that is consistent and he doesn't do well with change.

-- FSN_Interview 8

They are bringing up his chronological age and his not meeting the standards of his peers but by his adjusted age he is doing well.

-- FSN_Interview 21

We wish in addition to the social-emotional focus at CDC that there would have been additional focus on pre-academic skills to help him be more prepared for public school.

-- FSN_Interview 16_Foster

I would just change the way they assess it. They have these guidelines for assessing, and they tell you what is going on but don't really tell you the root problem.

-- PH_Interview 8

I also asked for speech and occupational therapy but they got very frustrated with him, he screams constantly and he didn't know what to do, sometimes he has cried for 6 hours at a time.

-- FSN_Interview 40_SP

The person providing the therapy was only teaching him one thing, out of 5 toys she would only pull out one, it was boring for him, she only pulled bubbles out and asked him to say bubbles. And then another session at the same clinic but it wasn't with the same person, so he was seen by another person and it was a different experience he was fascinated. Mom tried to switch therapist, but she was full. Mom decided not to go back to therapy and wait for him to start attending (preschool).

-- CBP_Spanish Interview 4

IDEA Part B/Exceptional Children

Some respondents reported that IEPs and therapists accessed through schools were helpful:

Preschool teachers and PT and OT therapists were really helpful once he had a diagnosis.

-- FSN Interview_31

He didn't want to go out because of Covid-19. Thanks to his EC teacher now we can go for walks and feel more relaxed. The teacher has provided supports and accommodations so that my son understood the situation of the corona virus. Since he did not want to leave the house, this was stressful for me, and the support that she offered was very helpful to me.

-- FSN_Interview 40_SP

It was a team effort with the school counselor, doctor and social worker sending the person to my house to give me the help I needed. I liked the support and to know that I wasn't alone.

-- PH_Interview 2

The school gave my son some counseling because he was a little wild, so that was good.

-- FSN_Interview 9

Therapy is helpful, OT and ST.

-- FSN_Interview 7

When they were little, it was hard for me to accept that they had a disability and the EC teacher made me feel at ease. Now my son wants to go to school.

-- FSN_Interview 40_SP

I'll have to say our participation with our children's IEP teams has been very beneficial for us and our children.

-- FSN_Interview 16_Foster

One EC teacher at school interacted with him and spent time trying to figure it out. She urged us to have him tested. She was helpful because she explained we needed to figure out what he needed, not just push IEP.

The therapist helped by telling me what I should be doing. Therapist helped talk to the school about it to figure out what was happening that caused the meltdowns.

-- FSN_Interview 20

Affordability, Eligibility, Accessibility:

His therapists – OT and PT – helped him physically and emotionally during therapy sessions, but we no longer have Medicaid, and they say he has met his goals and they don't know what else to do for him. I wish more programs were available and that cost would not be a factor for working families that don't qualify for Medicaid.

-- FSN Interview_29

We were getting ST and OT until we moved to NC and my husband's insurance changed and we can't afford therapy. He will have therapy now that school has started back. We don't qualify for Medicaid and the therapies are more than we can afford privately.

-- FSN Interview_35

Right now, it has been hard with this whole IEP situation, especially being that COVID19 has made it difficult to get that accomplished. I feel like he needs – I want to see if there are any issues that need to be addressed. On the computer, his attention span is off and stuff and it is hard for him to catch what is happening online.

-- FMF_Family 30

The local school system can't make home visits at this time and he doesn't focus on virtual learning due to his vision and hearing so we declined school services. CDSA staff and therapists were very helpful and we need support when we age out of their services not just school services.

-- FSN_Interview 38

The new school year within the public school system is focusing more on his needs through the IEP, but that is this year. We had a lot of difficulties last year, and I firmly believe it has been better because of the information and support I have received from Family Support Network.

-- FSN_Interview 41_SP

I don't think we got supports fast enough. His diagnosis has been identified for over a year. I finally wrote to request 504, for evaluation and observation. He now has a therapist, speech therapist. I was told by the school that he did not need speech therapy because his speech wasn't bad enough. He now has teletherapy 2 times a week in ***. I would like a safe adult to be able go with him when he is upset and help him to calm down.

-- FSN_Interview 20

Then it got really bad and they called me because they had to restrain him so I wish there were earlier supports before things became such a big problem.

-- FSN_Interview 26

Other issues with IEPs, school services:

School is more academic-focused, not on friendships. We only hear when there is a problem, and then I have to reinforce it with social stories. We actually put it in his IEP to address peer relationships and social stories.

[We need] great communication. We use a binder to keep all his evaluations, IEP, teachers, doctors and everything that is going on with him, including courses and free knowledge or opportunities for his therapist teachers and doctors.

-- FSN_Interview 7

What he’s going through with his IEP and things – I went through the same thing… Once I got the help that I needed, I excelled at everything that I needed. The next person might think he can’t learn but I know his potential. … I know what was done for me and so I try to be there for my son like that. Even though it hurts and you don’t hear as much problems from other kids.

-- FMF_Family 4

Not knowing exactly how to navigate his IEP with different therapists, different teachers and different situations, home vs clinic and which is most appropriate for him. I wish more people would actually listen to us when we voice our concerns. We have to be his parent and advocate, sometimes we would benefit from having a coordinator to help us understand the next process.

-- FSN Interview_33

Also that the school provide more social-emotional support even when the traumatic experiences happened outside of school, that this be part of the integration of services provided to the child.

-- FSN_Interview 40_SP

I have been told that my child is on the higher end of a SPED group and doesn't really need services, yet he still struggles and the SPED dept acts like there is only two categories of help. It has been very frustrating to advocate for my child when he is either viewed as a difficult child or that he is too high functioning. I believe he is on the spectrum and that is exactly what it is – a spectrum. Every person has differences and some similarities. (…) It's almost like school staff would try to understand him more if he had a diagnosis.

-- FSN_EngSurv66

The family survey asked about where respondents would like to use services – home, doctor's offices, or school/child care:

Where would you use services?

	Would you use services at your child's school or child care?	Would you use services through your child's doctor?	Would you use services at your home or where you live?	Number Surveyed
All	60.9%	33.3%	78.3%	138
African-American/Black	61.5%	30.8%	53.8%	13
Latinx (English)	78.6%	50.0%	85.7%	14
Latinx (Spanish)	64.1%	20.5%	79.5%	39
Native American	80.0%	80.0%	60.0%	5
White	53.1%	36.7%	79.6%	49
<50% FPL	52.0%	60.0%	64.0%	25
50-100% FPL	56.3%	28.1%	87.5%	32
100-150% FPL	66.7%	33.3%	86.7%	15
150-200% FPL	57.7%	19.2%	80.8%	26
>200% FPL	80.0%	30.0%	80.0%	10
Male	57.1%	21.4%	71.4%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Highest number would like services at home (78%). More than half would use services at school/child care (61%), and respondents were less interested in services through doctor (about one-third).

- Race: More than half of respondents in every group are interested in services at school or child care. Native American (3 out of the 5) and Latinx (English) (79%) respondents are the ones most interested in help from school/child care. Black respondents are most interested in services at school, then home, then doctor. Hispanic (both) and white respondents are most interested in services at home, then school, then doctor. Native American respondents are interested in school and doctor, then home.

- Income: Highest income bracket is very interested in services at school/child care, but more than half of every group is.

- Gender: Male responses are similar to the overall responses.

Care Management

CMARC coming for my newborn helped with all my kids.

-- FSN_Interview 2

Family members want support to navigate the system:

Q: What would be your ideal experience of support for yourself?
A: Having a support person that is with you throughout the process.

-- PH_Interview 14

My caseworker assigned to me through Coastal Horizons is available 24/7 which is a great support to me, just knowing there is someone there.

-- FSN_Interview 15

When I started working with the county I felt supported. That was a connection and they understood my situation. There were trained people and I knew I was in the right place. The person who carried out the process was very attentive to me and my child and I felt good. They were available. Once he turned 3 they couldn't help anymore, which seemed unbelievable that after so much work they would just leave us alone. The child was small and we didn't know what to do. I felt afraid without knowing how to do everything because the coordinator was the one who organized everything, made phone calls and made me feel taken care of.

Focus more on educating parents, to give them greater awareness and knowledge of the supports and the system. The hospital gives you a book and tells you how to manage things day-to-day but they don't guide you or talk to you about how the system works. You have to choose a pediatrician alone, no one helps you. You aren't born knowing all of these things and knowing how to be a parent. You also have these barriers in the system that aren't clear. You don't know what resources exist, when you can receive them or when your children can receive them.

-- CBP_Spanish Interview 2

Having a place that you can go to get information about where the services and resources are, what they do. A guide or tutor that can help you find the services you need in various areas – to help people navigate that system – and help you make sure you receive them, rather than having to work through everything alone. It would help if the guide spoke Spanish and understood your culture and background. They should understand the Hispanic community and make the system make more sense to the Hispanic community.

-- CBP_Spanish Interview 6

I wish more people would actually listen to us when we voice our concerns. We have to be his parent and advocate, sometimes we would benefit from having a coordinator to help us understand the next process.

Services based on income and the stringent Medicaid guidelines and waiting for services, being turned down, reapplying and they lost your paperwork, restarting the process over and over and having everything put in limbo for a while. CAP-C is very challenging and it would be helpful to have someone help navigate all the paperwork because if an answer has been left blank or answered incorrectly the process starts all over again. Not sure if the people who are making the decisions are being judgmental or just want the family to give up.

-- FSN Interview_33

We lost a lot of support once he aged out of Early Intervention Services and had to coordinate a lot of things on our own without knowing how.

-- FSN_Interview 38

Issues with Care Management:

It was not easy to obtain services/resources when we recognized the need. Before she had the same doctor for her whole life. When we arrived here we had a new pediatrician who did things differently. She was going to refer us to Community Care of North Carolina. I talked to the nurse but she didn't do it. They never came to do the evaluation and when we talked to them the nurse said that everything was fine. Later they sent a letter saying that we were no longer going to receive the services, even though we had never received anything to begin with. I had to keep calling and searching services for over a year. They didn't refer us. When we went back to see the doctor, she told me to register in a pre-kindergarten program and do an evaluation. They assessed her and I had to send many, many documents to register.

-- CBP_Spanish Interview 6

Usually the good people are the ones who don't have the ability to make the decisions; due to policy/procedures they can't do much.

-- PH_Interview 5

Having to jump through hoops to get resources [is a barrier]. Having to go to multiple agencies to meet one need.

-- PH_Interview 3

I couldn't communicate with the coordinator. They were very nice people, but you couldn't communicate with them and it was hard because I was very interested in the services.

-- CBP_Spanish Interview 7

I wish I was provided with more information about the child when they are placed with me. I oftentimes feel like I'm going in blind. A number of times my experience with CC4C workers have been challenging, in that it feels like I'm pulling teeth to try to get information which will be helpful for me as the primary caregiver. I've had some good experiences with CC4C workers as well.

-- FSN_Interview 11_Foster

Just not knowing what is out there [is a barrier]. I feel that the doctor should let you know of services such as PAT, CC4C, or P2P.

-- FSN_Interview 3

They need to be more concerned, and not just doing a job. If the person cares, she can make a difference in our life. Unfortunately, I have gotten 2 case managers who were very unconcerned. When the job was up, it wasn't about us anymore. Just a little more caring, more concerned.

-- PH_Interview 8

Medical Home/Pediatricians

Pediatricians were often mentioned when respondents were asked who helped them learn how to support their child's social-emotional development or to discuss a time they felt supported:

Her first pediatrician we were on a texting/calling basis. The first three months of ***'s life were very difficult. She was just so there for me.

-- PH_Interview 12

The doctor told me at her age, and that its very normal for her to be going through what she's going through.

-- PH_Interview 16

A doctor at *** told her issues will go away. It won't be like this always. Child is making progress and can make more progress.

-- FSN_Interview 25

Pediatricians: They always ask if I need help and offer advice. I talked to the pediatrician. She told me everything he was going through was normal. She helped me a couple of exercises. She didn't feel he needed a psychologist.

-- PH_Interview 6

Who helped me most was the pediatrician. From the beginning the pediatrician has been good with the child, she let him use the stethoscope and their relationship was very nice. Here in this country, they try to help so that the child has the best possible development.

-- CBP_Spanish Interview 1

I told the doctor to send me to all of the specialists that I needed and he did it. When I told the pediatrician that I needed a specialist, she referred me to a place, they did a hearing exam, a vision exam, and a speech exam. It was because the pediatrician sent me.

-- CBP_Spanish Interview 7

With her doctor it looks and feels great because her doctor genuinely cares.

-- FMF_Family 16

I definitely got good support from his doctor.

-- FMF_Family 19

My daughter had been seeing the same doctor since she was born and I had set up for their physical for school. I told the new doctor that he had some hard time focusing and she saw him and gave me a referral. They brought it up; I said please give me the evaluation so I can see if there is any reason why that's the way he does. It's quite normal for kids at this age but she gave me the referral.

-- FMF_Family 29

My boys' doctor. I've had the same doctor since high schooler was 3. With everything that was going on, she knew about it and she knew it was stressful for me. When we finally moved into our apartment, she was one of the first people to come. She brought diapers, toys for my infant. Another nurse at the clinic where she works got dishes for us.

-- FMF_Family 26

His doctor is very supportive. They give me extra milk and extra resources.

-- FMF_Family 3

His doctors. I could call and say something is wrong or something is up and they make sure that his needs are met.

-- FMF_Family 4

The kids' pediatrician – we've seen her since my teenager was 3. Her bedside manner is above and beyond. When we're worried or stressed out or our nerves are shot, when we're trying to navigate the stuff with ***, she always leaned in with compassion and empathy. She never discounted that we were worried about our kids. She always helped us to look outside the box so we would be better equipped to respond to the circumstances. She has kept up with our homelessness and our circumstances and never forgetting to ask how were we and if there were other supports she could offer even if they were outside of her realm.

In a world where we're Black and she's white, blonde and beautiful, she always gives us this utopic vision of the world. She's always made us feel love. She's made us feel human and whole and okay and wise and reasonable as parents worrying about their kids every time.

-- FMF_Family 6

My pediatrician has been with him since he was born and has helped me in stressful times.

-- FSN_Interview 38

We've had good experience with some of the pediatricians for the children placed with us.

-- FSN_Interview 13_Foster

The doctor tells me to calm down and take it easy and spend extra time talking with me. Once a pediatrician told me to call him whenever I felt it was needed, that meant a lot.

-- FSN_Interview 14_Foster

*** Private Practice is wonderful, solid, they go above and beyond. The therapist is awesome, even shared his phone number in case I need help.

-- FSN_Interview 20

Current primary care doctors roll out the red carpet for him. They worked with her fears. Gave her reassurance. She was afraid of going into the waiting room with her baby so she would wait in the car. They would call her when it was their time. They spent time with her and were always current with the information about her son. If she called the office with a question the doctor always returned the call.

-- FSN_Interview 21

Ninety percent if the time I felt the pediatrician understood my struggles. It was mother to mother. She understood my problem adjusting from one child to two. She knew what I needed to hear had good insight. She really cares. It shows in her eye contact, tone, and gestures. She shared her personal story about her adjustment to a new child. She empathized with me.

-- FSN_Interview 24

We had a pediatrician that really listened and was comforting.

-- FSN_Interview 26

We now have an amazing new pediatrician. Mom received her name from the *** Autism Group. This doctor took on the whole family. She paid attention. Dad even joined them. She gives Mom a choice for when to do testing. Dr. is ready to get the ball rolling. Shows no apprehension in hearing their concerns.

-- FSN_Interview 28

When my son was younger, he was going to have to go through a procedure. I was scared and felt alone. The doctor was a lot of help because he explained to me step by step of what was going to happen. He gave me the information I needed to understand. He helped me understand that it was not my fault or something I had done wrong.

-- FSN_Interview 1

Family members need pediatricians who speak their language and understand their culture:

Honestly for things related to health it has been the pediatrician or some other kind of helper. As a mom, the way that I grew up isn't the same as things are now and it wouldn't work. For that reason, I prefer to look for other advice and guidance. In NY the pediatrician was from El Salvador. We had a good relationship and I trusted him a lot and he gave us a good perspective. Here not so much because we have switched between pediatricians. With my daughter we had a provider from *** who came to the house. They were Colombian and we felt comfortable and good with them.

-- CBP_Spanish Interview 3

The pediatrician referred us to this clinic. There was someone who spoke Spanish at the front desk, but not anymore.

-- CBP_Spanish Interview 4

When I arrived to NC, I would have liked my son to be cared for by a pediatrician, despite the racism. Everything would have been faster, and the services would be put in place before all this COVID started. However, it was not so, and with the COVID, everything got delayed. My child was not treated by a pediatrician, instead he was assigned to a family doctor. Later I knew that the pediatrician in my area does not care for a certain group of people of specific races, such as the Hispanic. And the Medicaid provider assigned the Hispanic families to family doctors. Neither with the doctor nor with the school I have received any support.

-- FSN_Interview 41_SP

Before, she had the same doctor for her whole life. When they arrived here, they had a new pediatrician who did things differently.

-- CBP_Spanish Interview 6

As a baby, he had a real good Dr., but there was an error with the insurance, and they were charging us a lot of money for the services for a whole year. Because of that we decided to leave, and I had to switch him. I loved how she explained things to me. It's a lot easier to understand them.

-- CBP_Spanish Interview 5

Issues with referrals:

Initially her pediatrician told her not to worry about it. At another visit when it was discussed the doctor referred her to CDSA. Mom would have liked a referral sooner.

-- FSN_Interview 27

The pediatrician gave me referrals to providers I wasn't comfortable going to. I wish pediatricians had more expertise in other services to refer to.

-- FSN_Interview 26

Having to go through doctor or waiting such a long time to get an appointment. There needs to be a way of getting child seen sooner.

-- FSN_Interview 25

The system needs to change. You should not need a doctor's referral. Should be able to request an appointment without one. Perhaps a simple screening to see if they meet criteria

-- FSN_Interview 24

Family members want to be active partners in their children's care and feel respected:

Their pediatrician was very dismissive of their concerns. Would not give references or referrals. Son had a head injury at age of 3 that required ER visit and stitches. There was no traumatic brain injury follow-up. Dr. saw no need for testing for a diagnosis. After he received his diagnosis the doctor released them. She said she did not feel she could help him. Receiving the diagnosis gave his Dad an understanding of his son's problems and he immediately apologized for his actions and they established a father/son relationship. If they had started the process earlier, he might now be in a traditional setting.

-- FSN_Interview 28

I feel like we have a great partnership with our doctor. We had to switch doctors cause they weren't taking my concerns into consideration and we now have a doctor that anytime we have any concerns she will listen and even if she doesn't agree she will tell me why but even they she still leaves it up to me so we work together. We do have a great partnership.

-- FSN_Interview 8

Good communication and the ability to ask questions and frequent updates from our children's teachers and/or therapists is important.

-- FSN_Interview 16_Foster

Lack of communication with the pediatrician is also an issue. The appointment is very short. Sometimes you only get to say and that's it. Sometimes I didn't have time to ask the questions that I had. Giving more time to the patient, and listening to me, not just me listening to him.

-- CBP_Spanish Interview 7

His doctor said he would grow out of it, eventually. I knew he would not. I didn't think he understood my concerns.

-- FSN Interview_31

After lots of searching, I have finally found a doctor that listens to me and understands my concerns as her mom rather than just being judgmental because of their medical background. It looks much better now than when she was younger and I really needed the support. As a young mother, I think they dismissed lots of my concerns.

-- FSN Interview_33

I ask a lot of questions and sometimes teachers and doctors don't want you to ask them questions.

-- CBP_Spanish Interview 4

I went to his pediatrician and they told me there was nothing she could do. When I told the pediatrician she just kept saying he is just being a child but I know something is wrong. I just wish she would have understood me. I just felt like she wasn't listening to what I was saying. She didn't care about my needs.

-- PH_Interview 14

I did not want to be discounted. I would wonder about something different like a medical reason and the doctor would say "we might think about it, but I don't see it." I don't feel they really considered what I thought about it sometimes.

-- FSN_Interview 24

Family members want pediatricians to connect them to resources:

The way the information is given out. There are a lot of services and programs that I'm not aware of. I know there are a lot of brochures out there but I feel us (Hispanics) are more unlikely to pick one up. Most doctors' offices have a tv, maybe it would be a good idea if they would post programs and services on there so we can automatically see it. Or maybe the doctor could mention a couple at the time of visit.

-- FSN_Interview 1

Just not knowing what is out there. I feel that the doctor should let you know of services such as PAT, CC4C, or P2P.

-- FSN_Interview 3

It is important that there is more information, that families know and pediatricians can facilitate this more.

-- CBP_Spanish Interview 7

Issues with Accessibility, Reliability, Quality:

We had a situation with a pediatrician but now have a new one. What has been difficult living in ***, is that it used to be small and locally owned. Now that everything is growing and expanding so fast. When outside people come and take over things like the pediatrician there were problems (i.e., they were not flexible with appointments).

-- PH_Interview 7

Q: If you could wave a magic wand, what is something that should be changed or fixed about the early childhood social-emotional health system?
A: The sensitivity and time with the pediatrician. That they show interest for the patient.

-- CBP_Spanish Interview 7

Providers should have background in child development so they know what is appropriate.

-- FSN_Interview 24

The family survey asked a question about where respondents would like to use services – home, doctor's offices, or school/child care:

	Would you use services at your child's school or child care?	Would you use services through your child's doctor?	Would you use services at your home or where you live?	Number Surveyed
All	60.9%	33.3%	78.3%	138
African-American/Black	61.5%	30.8%	53.8%	13
Latinx (English)	78.6%	50.0%	85.7%	14
Latinx (Spanish)	64.1%	20.5%	79.5%	39
Native American	80.0%	80.0%	60.0%	5
White	53.1%	36.7%	79.6%	49
<50% FPL	52.0%	60.0%	64.0%	25
50-100% FPL	56.3%	28.1%	87.5%	32
100-150% FPL	66.7%	33.3%	86.7%	15
150-200% FPL	57.7%	19.2%	80.8%	26
>200% FPL	80.0%	30.0%	80.0%	10
Male	57.1%	21.4%	71.4%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Highest number would like services at home (78%). More than half would use services at school/child care (61%). Respondents were less interested in services through doctor (about one-third).

- Race: Four out of the 5 Native American respondents and half the Latinx (English) respondents are interested in services at the doctor's office. Respondents of other races/ethnicities less so. Black respondents are most interested in services at school, then home, then doctor. Hispanic (both) and white respondents are most interested in services at home, then school, then doctor. Native American respondents are interested in school and doctor, then home.

- Income: Most of those in extreme poverty are interested in services at the doctor's office, which is very different from rest of the income brackets, where less than a third are interested in services at the doctor's office.

- Gender: Male responses are similar to the overall responses, except their interest in services at the doctor's office is even lower (21%).

The family survey also asked about eligibility, referrals and waitlists being barriers to accessing services:

	I was overwhelmed by the amount of information I received when I shared my concerns with the doctor, teacher or other service provider?	I was told I or my child didn't qualify for some services, and I didn't know what I could do to get them?	My child received a service, but then I did not receive a follow up appointment or a referral for additional services?	I received a referral for a follow up or an additional service, but I was not able to or decided not to access it?	I received a referral for a follow up or an additional service, but the other program did not follow up with me?	I received a referral for a follow up but the times of day for that follow up did not work for me?	Number Surveyed
All	13.0%	10.1%	7.2%	2.2%	4.3%	6.5%	138
African American/Black	15.4%	7.7%	7.7%	0.0%	7.7%	7.7%	13
Latinx-English	14.3%	7.1%	0.0%	0.0%	0.0%	7.1%	14
Latinx-Spanish	7.7%	7.7%	7.7%	2.6%	5.1%	7.7%	39
Native American	0.0%	20.0%	0.0%	0.0%	0.0%	0.0%	5
White	18.4%	14.3%	10.2%	4.1%	4.1%	2.0%	49
<50% FPL	4.0%	4.0%	8.0%	0.0%	8.0%	8.0%	25
50-100% FPL	12.5%	3.1%	9.4%	0.0%	0.0%	6.3%	32
100-150% FPL	13.3%	13.3%	6.7%	6.7%	6.7%	6.7%	15
150-200% FPL	7.7%	15.4%	0.0%	3.8%	0.0%	3.8%	26
>200% FPL	30.0%	10.0%	0.0%	10.0%	0.0%	0.0%	10
Male	14.3%	14.3%	0.0%	7.1%	0.0%	0.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

The items noted by the most respondents include feeling overwhelmed by the amount of information provided (13%) and being told a child does not qualify for services (10%). Out of the four questions about referrals:

- 7% report not receiving a referral.
- Only 3 respondents received a referral but didn't end up accessing the service.
- 6 respondents reported that they received a referral but no follow up.
- 7% received a referral but the scheduled day/time didn't work for them.

- Race: White respondents are most likely to report feeling overwhelmed by the amount of info (18%), followed closely by Black (15%) and Latinx (English) respondents (14%). One out of the five Native American respondents noted that they were told a child didn't qualify for services. White respondents reported that at about double respondents of other races/ethnicities, but due to small sample sizes, this may not be significant.

- Income: Very few people in each income bracket noted this an issue (only 1-3 people), which prevents useful analysis.

- Gender: Same as for income. Only 1-2 men noted these as issues.

Family voice on eligibility:

Therapy before there are issues.

-- FSN_EngSurv33

More providers and longer access to care no matter their age.

-- FSN_EngSurv28

The provider is trying to tell my child doesn't need more support and is trying to exit her from her programs despite the fact that my child has not been able to meet all of her written goals.

-- FSN_EngSurv77

Much of the resources we've found are for children with Autism either explicitly or that was made clear in the service providers terminology. My child does not have autism, and therefore those services did not seem appropriate to him.

-- FSN_EngSurv60

The in-home services my son had ended abruptly when he was 3 years old. That is way too young. Even at 3 years old mentally he was only about 1.

-- FSN_EngSurv58

I have been told that my child is on the higher end of a SPED group and doesn't really need services, yet he still struggles and the SPED dept acts like there is only two categories of help. It has been very frustrating to advocate for my child when he is either viewed as a difficult child or that he is too high functioning. I believe he is on the spectrum and that is exactly what it is a spectrum every person has differences and some similarities. (…) It's almost like school staff would try to understand him more if he had a diagnosis.

-- FSN_EngSurv66

Family voice on waitlists:

As a mother I try my best and do research to try to help him so he can become a fully adjusted adult but I know that I don't know half as much as the professionals and to hear that it will be years until he has access to these programs could mean that these habits and behaviors are going to be embedded too strongly and for too long to be unlearned.

I was told about a program that could help my child and different parts of his life and have been on that list waiting for services for years now and when I called back a couple years later to see if anything changed, I was told it would still be years until he could have access to these services.

-- FSN_EngSurv58

The time that it takes to access or qualify for these services.

-- FSN_SpSurv7

That room can always be found/available so they can be attended to.

-- CBP_SP14

Family voice on referrals:

That the professionals will be more conscious to the parents' concerns for them to be more effective providing the referrals.

-- FSN_SpSurv12

It was unfortunate after the 2 years I asked for more testing that it took my son attempting to hurt himself to get a referral for further testing.

-- FSN_EngSurv66

Doctor not wanting to refer for services and telling me that nothing's wrong.

-- FSN_EngSurv18

Help with appointments. Appointments being made the same day.

-- FSN_EngSurv5

Prompt responses… been the hardest part getting return calls.

-- FSN_EngSurv16

Receiving the information for programs and supports as soon as possible.

-- FSN_EngSurv47

It's also important that providers are proactive in the decision making and knowledge sharing in order for my family to receive quality care in a timely fashion.

-- FSN_EngSurv54

Health Insurers

Some family members reported that Medicaid is helpful:

So far, I have had a ton of help through my Medicaid. It has helped in many different facets. She has a wonderful daycare that is provided through Medicaid and vouchers. Medicaid is paying my rent.

-- PH_Interview 12

I also get Medicaid. I am worried that will get taken away when I start working. It seems kind of backward, that you can sit at home and get benefits and once you start working some you lose a lot.

-- PH_Interview 13

Through my in-laws, we were connected with a therapist. The girls didn't have Medicaid and the lawyer advised us not to apply for Medicaid. Eventually we got it, but before that we couldn't do anything. The therapies are invaluable – you can't put a price on them. After a year and a half of fighting we were able to establish residence, get Medicaid, and use the services.

-- CBP_Spanish Interview 6

Medicaid and WIC they were helpful, and mom was glad she was able to get the services. She was pleased with all the programs and services she has received, and got very good support

-- FSN_Interview 5

If I had a magic wand, I would give Medicaid automatically to all the children that have any type of special need or disability and that way they can acquire services for their well-being in different areas.

-- FSN_SpSurv10

Issues with Medicaid:

The Medicaid card was not up to date (wrong county). Got very frustrated with the doctor's office—they helped her get into a different doctor's office. The doctor's office and staff really helped her through that.

-- PH_Interview 15

We'll advocate for the children in our care and really get frustrated especially when a service need is identified and then Trillium denies those services. Medicaid oftentimes it seems get the least experienced service providers.

-- FSN_Interview 12_Foster

I wish that I didn't have to keep applying for Medicaid. My son has a rare condition where we know he will need services for the rest of his life, and for me is stressful having to apply every year.

-- FSN_Interview 6

Among the many situations, one of them is that I have to travel an hour to receive services because the services are not provided in my area, because of the language barrier. I do not have my own transportation, and I have to deal with Medicaid to provide transportation.

-- FSN_Interview 41_SP

We have seen a variety of counselors and they either didn't work, etc. We are currently using one but it is via zoom and not every provider took Medicaid.

-- FSN_EngSurv4

My foster daughter is on Medicaid and the services she needs are often not covered because providers are so limited.

-- FSN_EngSurv13

Comments specifically about Medicaid Innovations Waiver and CAP/C:

We found out about Innovations Waiver wait list early on and had him put on it at 18 months. He now has respite and developmental therapies. Empower Camp and after school program. We chose the worker and had her hired through the company, so the interview process was smooth to get a worker. Don't feel the set up was difficult.

-- FSN_Interview 18

I did learn about the Innovations waiver grant through the resource café website now but it is a long wait.

-- FSN_Interview 7

You don't want me to get started on the Innovations Waiver waiting list. By the time he is approved he will be an adult, and I need help now. The wait for the Innovation waiver is unreal. We had a long wait for ABA therapy even after his diagnosis and the cost of therapy was difficult until I could get his Medicaid. We had to fight to get ABA therapy and some respite. I had to reduce my hours at work to qualify for Medicaid as a single mom with one income of $300 weekly and some meager child support from his dad because I made too much money to qualify for even food stamps. I need more Respite to help him socialize more. It should not be so difficult.

-- FSN Interview_31

The waiver system needs to be addressed.

-- FSN_Interview 23

I have had good and bad experiences. Some services have been difficult to get. I have looked in the community to see what kind of services they offer. Nobody is going to tell me where I could go get the services for my kids. There are other counties that offer the services you cannot find in your county and if there are, you're put on a waiting list. I would like my kids to have the Home Skill service, but because he doesn't have a waiver, he cannot have it.

-- FSN_Interview 40_SP

CAP-C and SSI was paperwork, denial, more paperwork, lost paperwork, denial and more paperwork.

Services based on income and the stringent Medicaid guidelines and waiting for services, being turned down, reapplying and they lost your paperwork, restarting the process over and over and having everything put in limbo for a while. CAP-C is very challenging and it would be helpful to have someone help navigate all the paperwork because if an answer has been left blank or answered incorrectly the process starts all over again. Not sure if the people who are making the decisions are being judgmental or just want the family to give up.

Have less hoops to jump though for 551, Medicaid and CAP-C and shorten the waiting periods or have emergency or alternate programs to use until a decision is made so things are not in limbo.

-- FSN Interview_33

Issues where it is unclear whether public or private insurance:

As a baby, he had a real good doctor, but there was an error with the insurance, and they were charging us a lot of money for the services for a whole year. Because of that we decided to leave, and I had to switch him. I loved how she explained things to me. It's a lot easier to understand them.

-- CBP_Spanish Interview 5

I would have liked for there to be more therapy. They have been very helpful but we can't receive more.

-- CBP_Spanish Interview 8

I've had people bill my account for medical services but I didn't receive any help.

-- FMF_Family 13

As far as emotional support programs, some offer more support than others. Some are just there to receive the insurance money. Some really just want to help you.

-- FMF_Family 29

Q: What things have made it difficult for you to access programs, services or supports for your child's social-emotional development in the past or right now?
A: Insurance!!! It takes the longest to approve anything; we had a bath chair that was ordered. It was 9 months before we got it and by than we didn't need it. Insurance has been our biggest downfall.

-- FSN_Interview 8

I looked for another agency to work with him and they could have sent him out the next day, but it took 6 months for my insurance to approve for him to work with my son.

-- FSN_Interview 10

Affordability of services without Medicaid:

I feel like me having a job has been a barrier. Everything is income based. He was never eligible for SSI, Medicaid making services too expensive. My child still deserves services but can't get all services needed.

-- FSN_Interview 18

If you couldn't afford treatment, insurance proved to be very expensive.

-- FSN_Interview 23

If you do not qualify for Medic[aid], then must pay out of pocket for any services.

-- FSN_Interview 24

Money, being in between. Making too much for Medicaid but not enough to pay out of pocket.

-- FSN_Interview 26

His therapists – OT and PT – helped him physically and emotionally during therapy sessions, but we no longer have Medicaid and they say he has met his goals and they don't know what else to do for him. I wish more programs were available and that cost would not be a factor for working families that don't qualify for Medicaid.

The lack of Medicaid makes the cost of all his services so difficult when we are a one income family and can't afford any extra expenses. It is financially hard on us to travel to Chapel Hill and Boston for his medical appointments. I don't have insurance so I can afford to go to counseling.

-- FSN Interview_29

We were getting ST and OT until we moved to NC and my husband's insurance changed and we can't afford therapy. He will therapy now that school has started back. We don't qualify for Medicaid and the therapies are more than we can afford privately.

-- FSN Interview_35

CDSA was not helpful and they were mediocre with therapies. It was cheaper for me to direct pay for therapies through my insurance than to use their sliding-fee scale. They told me that I couldn't check out things like 'Signing Times" videos because my child didn't have Medicaid.

They are missing the boat with middle income families. They need to find a way to emotionally support, provide some skills training and tools for all parents. Not make them feel that just because they don't have Medicaid, they don't get anything. Need to better train Case Workers.

-- FSN_Interview 17

Evidence-Based Programs and Providers

Comments about specific Evidence-Based Programs:

Triple P classes [helped us].

-- FSN_Interview 17

We also enrolled in Triple P classes. I didn't feel support by the Triple P program. I wanted to talk more about my experiences but didn't feel comfortable.

-- FSN_Interview 24

My experience with PAT was great. I felt welcomed. PAT helped me get information about services I didn't know about. I just wish there were similar services for older children. Older children go through changes as well and we need more help so that we can understand them.

Just not knowing what is out there [is a barrier]. I feel that the doctor should let you know of services such as PAT, CC4C, or P2P.

-- FSN_Interview 3

P2P support group also made me feel really welcomed and supported. I wish they would have those meeting again.

-- FSN_Interview 4

Our local CDSA assessed the sibling pair and got services through Child First in place. The Child First worker was helpful who met with us prior to her time with the children and then following before she left.

-- FSN_Interview 13_Foster

Comments about psychologists, psychiatrists:

My son had a psychologist that came to my house. She taught me methods to calm him down when he was upset and to learn how to understand his feelings. Since he was a little boy, he couldn't talk and he was frustrated that I couldn't understand what he was trying to tell me.

I also asked for speech and occupational therapy but they got very frustrated with him, he screams constantly and he didn't know what to do, sometimes he has cried for 6 hours at a time. The Speech therapist gave me some brochures but they were only in English. The psychologist came to my house for a year. One of the things that she told me was the method 1, 2 and 3. It help me realize that my son Luis was frustrated and that he couldn't understand me. The Psychologist helped a lot. It makes my children see that there are things that can and cannot be controlled.

Psychologist - I wish she was close, she's too far away and I don't have her anymore because now I have ABA.

-- FSN_Interview 40_SP

His diagnosis of ADHD and bad anxiety added to all his medical diagnosis. His behavior was difficult and I didn't know what to do. The doctor suggested counseling. Counseling has been very helpful to both of us. I now have ways to treat his behavior and can understand it more.

-- FSN_Interview 36

I like the psychologist we found and the therapist was helpful but I had to do the research to find them. I feel the psychologist we started testing with gets what I am saying. Also, the Psychiatrist observed him and saw all the things I saw and helped. That kept me motivated to keep going and trying.

-- FSN_Interview 26

There is this one particular child psychologist with whom I have a lot of respect for. This psychologist takes the time to really listen and they come prepared for the child's appointment which shows how engaged they are, up to speed and have read up on the child and/or their special need.

-- FSN_Interview 11_Foster

When we came upon this excellent child psychiatrist at ***. They got the child's treatment team to finally get her to a psychiatrist who discovered the old records and made the correct diagnosis.

-- FSN_Interview 12_Foster

Some of our foster and later adopted children came to us with paperwork and diagnosis/services already in place. Two of our children are biological siblings who are now 13 & 15 years old but were 7 & 9 when they came to us. They had a lot of emotional issues with the trauma of being removed from their parents and then their subsequent failure to reunify. We worked closely with the psychologists and therapists to help them through this.

-- FSN_Interview 16_Foster

Need for therapy/counseling services for children:

Wish there was a kid's therapy—or a class that would help her child fully understand what she has been through and help her child process what they have experienced.

-- PH_Interview 15

If my son was able to talk to a therapist, and if meds were available.

-- PH_Interview 5

I would have liked for there to be more therapy. They have been very helpful but we can't receive more.

-- CBP_Spanish Interview 8

My ex was abusive. I felt my 2-year-old son needed therapy. People told me a 2-year-old would not remember those events. I don't think people understood that he needed help even when I thought he did.

-- FSN_Interview 20

Behavioral therapy, therapies are not easy to get due to income constraints.

-- FSN_Interview 17

Things like iCan Swim, iCan Bike, Dance, therapies like speech and things through the CDSA more accessible for working families. Respite care earlier on.

-- FSN_Interview 18

Need for therapy/counseling services for adults: 25 respondents commented in the open-ended section of the survey that they wanted therapy for them – more than any other single type of comment, except for parent support groups.

I came with a lot of fear after my first pregnancy. I was very alone in the process, I was in another country with a child and post-partum depression. So I had a lot of anxiety about the second pregnancy. I worried that reject the child and I started to blame myself, which was related to depression. But my doctors asked me about this and connected me to a psychologist who helped me.

-- CBP_Spanish Interview 2

She would have liked treatment herself, so she could process things that her son needed. Someone to talk to about your feelings as a parent.

-- FSN_Interview 21

More support for parents. Wish there were counseling and more support groups.

-- FSN_Interview 3

Therapist for caregivers to meet with occasionally.

-- FSN_EngSurv10

Therapy. Being able to speak to someone.

-- FSN_EngSurv31

Parenting support groups, Educational opportunities to learn about what to expect. Child care options. Therapy from doctors.

-- FSN_EngSurv47

More emotional support and counseling for parents. Someone to talk to, like a counselor just for the parents.

-- FSN_EngSurv70

Family therapy.

-- FSN_SpSurv10

The family survey also asked about eligibility, referrals and waitlists being barriers to accessing services:

	I was overwhelmed by the amount of information I received when I shared my concerns with the doctor, teacher or other service provider?	I was told I or my child didn't qualify for some services, and I didn't know what I could do to get them?	My child received a service, but then I did not receive a follow up appointment or a referral for additional services?	I received a referral for a follow up or an additional service, but I was not able to or decided not to access it?	I received a referral for a follow up or an additional service, but the other program did not follow up with me?	I received a referral for a follow up but the times of day for that follow up did not work for me?	Number Surveyed
All	13.0%	10.1%	7.2%	2.2%	4.3%	6.5%	138
African American/Black	15.4%	7.7%	7.7%	0.0%	7.7%	7.7%	13
Latinx-English	14.3%	7.1%	0.0%	0.0%	0.0%	7.1%	14
Latinx-Spanish	7.7%	7.7%	7.7%	2.6%	5.1%	7.7%	39
Native American	0.0%	20.0%	0.0%	0.0%	0.0%	0.0%	5
White	18.4%	14.3%	10.2%	4.1%	4.1%	2.0%	49
<50% FPL	4.0%	4.0%	8.0%	0.0%	8.0%	8.0%	25
50-100% FPL	12.5%	3.1%	9.4%	0.0%	0.0%	6.3%	32
100-150% FPL	13.3%	13.3%	6.7%	6.7%	6.7%	6.7%	15
150-200% FPL	7.7%	15.4%	0.0%	3.8%	0.0%	3.8%	26
>200% FPL	30.0%	10.0%	0.0%	10.0%	0.0%	0.0%	10
Male	14.3%	14.3%	0.0%	7.1%	0.0%	0.0%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

The items noted by the most respondents include feeling overwhelmed by the amount of information provided (13%) and being told a child does not qualify for services (10%). Out of the four questions about referrals:

- 7% report not receiving a referral.
- Only 3 respondents received a referral but didn't end up accessing the service.
- 6 respondents reported that they received a referral but no follow up.
- 7% received a referral but the scheduled day/time didn't work for them.

- Race: White respondents are most likely to report feeling overwhelmed by the amount of info (18%), followed closely by Black (15%) and Latinx (English) respondents (14%). One out of the five Native American respondents noted that they were told a child didn't qualify for services. White respondents reported that at about double respondents of other races/ethnicities, but due to small sample sizes, this may not be significant.

- Income: Very few people in each income bracket noted this an issue (only 1-3 people), which prevents useful analysis.

- Gender: Same as for income. Only 1-2 men noted these as issues.

Family voice on eligibility:

Therapy before there are issues.

-- FSN_EngSurv33

More providers and longer access to care no matter their age.

-- FSN_EngSurv28

The provider is trying to tell my child doesn't need more support and is trying to exit her from her programs despite the fact that my child has not been able to meet all of her written goals.

-- FSN_EngSurv77

Much of the resources we've found are for children with Autism either explicitly or that was made clear in the service providers terminology. My child does not have autism, and therefore those services did not seem appropriate to him.

-- FSN_EngSurv60

The in-home services my son had ended abruptly when he was 3 years old. That is way too young. Even at 3 years old mentally he was only about 1.

-- FSN_EngSurv58

I have been told that my child is on the higher end of a SPED group and doesn't really need services, yet he still struggles and the SPED dept acts like there is only two categories of help. It has been very frustrating to advocate for my child when he is either viewed as a difficult child or that he is too high functioning. I believe he is on the spectrum and that is exactly what it is a spectrum every person has differences and some similarities. (…) It's almost like school staff would try to understand him more if he had a diagnosis.

-- FSN_EngSurv66

Family voice on waitlists:

As a mother I try my best and do research to try to help him so he can become a fully adjusted adult but I know that I don't know half as much as the professionals and to hear that it will be years until he has access to these programs could mean that these habits and behaviors are going to be embedded too strongly and for too long to be unlearned.

I was told about a program that could help my child and different parts of his life and have been on that list waiting for services for years now and when I called back a couple years later to see if anything changed, I was told it would still be years until he could have access to these services.

-- FSN_EngSurv58

The time that it takes to access or qualify for these services.

-- FSN_SpSurv7

That room can always be found/available so they can be attended to.

-- CBP_SP14

Family voice on referrals:

That the professionals will be more conscious to the parents' concerns for them to be more effective providing the referrals.

-- FSN_SpSurv12

It was unfortunate after the 2 years I asked for more testing that it took my son attempting to hurt himself to get a referral for further testing.

-- FSN_EngSurv66

Doctor not wanting to refer for services and telling me that nothing's wrong.

-- FSN_EngSurv18

Help with appointments. Appointments being made the same day.

-- FSN_EngSurv5

Prompt responses… been the hardest part getting return calls.

-- FSN_EngSurv16

Receiving the information for programs and supports as soon as possible.

-- FSN_EngSurv47

It's also important that providers are proactive in the decision making and knowledge sharing in order for my family to receive quality care in a timely fashion.

-- FSN_EngSurv54

Early Education (child care, preschool and K-3 elementary school)

These comments are focused on child care/preschool/K-3rd grade supports that are NOT IEP/Part B/Exceptional Children (EC) services. Those services are being addressed in the Part B workgroup.

Many respondents reported that they wished there were more/better/more accessible child care services available to them:

Free child care (birth-15 years old).

-- PH_Interview 4

Daycare should be free. Period.

-- FMF_Family 15

Daycare: It has been really hard to get into. Wish it was easier. Interacting with other kids is so important. I had one kid that didn't talk until he experienced school.

-- PH_Interview 3

More affordable options for childcare and daycare.

-- PH_Interview 6

Help getting childcare more vouchers for childcare- even if the parent works. Childcare is expensive. The waitlists are really long to get vouchers too.

-- PH_Interview 11

One thing is that all children should be able to go to daycare, regardless of their background. That is the only way kids can get that socialization before they are thrown into school.

-- PH_Interview 13

My child is too young but high-quality early childhood education is important.

-- FMF_Family 22

High quality early childcare, cameras in the classrooms. They just let anyone teach.

-- FMF_Family 21

I know it is hard for me to find a babysitter for when I need to go to work. My mom is the only person I could 100% depend on to watch him. She's my go-to person to depend upon when I'm at work. If I had a better support system or person for when I'm going to work. I wish there were more developmental preschools available rather than public schools. Like the Easter Seals programs but even that is closing.

-- FSN_Interview 23

Affordable childcare because we literally went broke trying to put them places where we knew there would be a level of safety where we felt they would be educated well. Even with a voucher, we were still having to pay out of pocket. We really never have had the opportunity to balance out financially. We always made sacrifices for our kids starting with their education and care.

-- FMF_Family 6

If I was in a better situation, he would be at a better daycare. It would be a better outcome. I wish he were at a daycare that had a mix of different races. (Instead of only Black kids). I only chose that one because they offered transportation and this was the only option.

I would like for him to be at a daycare that did a better job supporting his social emotional development but I had to go with one that offered transportation.

-- FMF_Family 3

Better daycare with transportation

-- FMF_Family 11

Whenever we are around other kids, I see she gets really shy and will cry. I told the doctor about it and they said to sign her up for preschool. I didn't do it because it was already past sign up time and then it was hard for me to get there. She wasn't old enough for the one through school and the ones at churches were expensive and I couldn't get her there with work. I would make it less expensive and easier to sign up -- Preschools that aren't too expensive for me to pay for and that I can take her to. I have to work and it is hard for me to take her and pick her up.

-- FSN_Interview 19

I don’t have anyone who can help with childcare. It makes me anxious to leave them with someone.

-- CBP_Spanish Interview 2

In NY the daycares are in homes, and where we lived there was a big community and there were Hispanic communities. Here it is different. There are a lot of children for only two care providers and it feels robotic. The person who cares for them doesn’t have a connection and isn’t very caring. They feel cold and I didn’t want to leave my daughter in a place where the treatment was cold.

-- CBP_Spanish Interview 3

Available daycare or respite

-- FSN_Interview 42_Hmong

Child Care and preschool were supportive for some respondents:

She has a wonderful daycare that is provided through Medicaid and vouchers.

-- PH_Interview 12

With him going to daycare, the people there are extremely nice, they have a full deal with [homeless shelter] that all the kids go there. Sometimes other parents will look at us funny when we pull up in two big white vans, but when we go in there, they talk to us like any of the other parents. It has been nice in that regard.

-- PH_Interview 13

Last night—mom picked up my children from daycare and baby had thrush. Had never dealt with that. The staff helped her figure out what to do. The Medicaid card was not up to date (wrong county). Got very frustrated with the doctor’s office—they helped her get into a different doctor’s office.

-- PH_Interview 15

It was when I found *** Bilingual Preschool that helped. I think that with *** it helped her a lot and prepared us as well because it taught us how to deal with specific situations and later in the classroom, she learned that she wasn’t always going to be with her mother. The preschool offered many resources that were useful for our children. With the teachers at *** Bilingual Preschool there is confidence and trust and they tell me the things that she was done. I think it is very important that there is a strong trusting relationship. Personally, I think the school offers many tools.

-- CBP_Spanish Interview 3

When we went back to see the doctor, she told me to register in a pre-kindergarten program and do an evaluation. They assessed her and I had to send many, many documents to register. Later I found *** Bilingual Preschool and the family program and I waited for a space there. I was able to come two times per week and volunteer and leave my daughter to play with others at the preschool. We could both benefit. The therapists at *** Bilingual Preschool, it was difficult for us to find them, but they have been helpful. They were bilingual and multicultural and they helped.

-- CBP_Spanish Interview 6

When we arrived at *** Bilingual Preschool everything changed. I have felt supported, understood, loved. I have felt that my daughter has been loved and at the preschool I learned what it meant to have a good relationship with a teacher. Because of that I have made an effort to communicate with other teachers.

-- CBP_Spanish Interview 7

It helps when you see that they teachers help and don't discriminate against my children. I feel like they really care about them.

-- CBP_Spanish Interview 8

Teachers were very patient with both of us. I talked with her teacher and let her know what was going on.

-- FMF_Family 16

I feel good about Early Head Start.

-- FMF_Family 3

When we moved here, she did NC PreK. They helped me a lot and supported me a lot. When my daughter was in NC PreK it was the staff that was really nice. They were very understanding and helpful. Like the teacher when she wanted to learn about our culture. Also, when my daughter was in preschool, teacher invited me to come and read a book in Spanish.

-- PH_Interview 7

Her daycare was real good about that. She felt valued. They listened to her and understood. The 3-yearold class was not doing well, they were having a difficult time keeping the students In line. She did not feel they were singling her daughter out. It was a class issue and they addressed her concerns.

-- FSN_Interview 27

As he got older more things became more apparent. I just kept noticing things that were difficult for him. His preschool teachers really helped steer us in the right direction for help and resources.

-- FSN Interview_31

Difficulties with child care and preschool:

Some of my friends have struggled with the PreK and HeadStart transition and trying to make sure that their kids are in something to be social that is not draining all of their paycheck. I know someone who is working her part time job just so her child can go to daycare. She doesn't even see income from this job.

-- PH_Interview 13

I spoke with the teacher, director, program coordinator, and regional manager for the daycare. They felt they were listening to me but I felt they weren't actually taking what I say into consideration. I said I am not denying my child is doing that but he isn't doing that at home. And I told them I was confused. Then I learned there were other things going on the classroom and that was causing the behaviors. Then I pulled him from the program. I left the daycare and everything was fine again. No issues when he started kindergarten. I met with the teachers many times to check in on behaviors and they didn't have any concerns.

-- PH_Interview 6

In daycare there was a period of time when the teachers said he needed a lot of attention and didn't follow the activities and I had a chance to see it through the camera. He never played with other kids or joined activities – he just did what he wanted. It was hard for him to stay there for the amount of time that teachers asked for – 8-10 minutes which was hard with his condition. It is difficult for him to spend 5 minutes in one activity. Even though I talked to the teachers, they keep treating him normally. We also didn't want to talk to teachers about it at first.

Teachers are an important resource in children's lives. From birth your children are with you, but when they are away from you later they act very differently and it is up to teachers to observe how they are behaving when you aren't there. Having help and support from the teacher is important to know how the child is behaving. Communication with teachers is important.

-- CBP_Spanish Interview 2

When I worked, I left him with a family member. If I had informed myself, I would had taken him to a daycare or taken him to programs in churches and I didn't due to fear of what could happen since I wasn't there to watch. To turn him loose it would had made a huge difference.

At [preschool through a school district], we had to drop him off at the door and we could not go to the classroom.

-- CBP_Spanish Interview 5

I'm starting to notice some changes in his behavior. He started to have more tantrums (even before baby was born). I think that is connected to the daycare. He is not experiencing socialization now that the older kids have moved up.

-- FMF_Family 3

It's appalling for this institution (Early Head Start) which is there to provide care and support for the most vulnerable children under the age of 5. We weren't going to walk away until Covid19. They were adamant that they had a right to tell us to go. You're not just doing this to appease me. I've read the laws. That was not a fun fight. And it definitely was a fight that ended abruptly and did not see itself to a finality.

-- FMF_Family 6

He didn't want to go to his summer pre-K daycare program. When I got there to pick him up there would be 3 adults there telling me how bad my son was. He bit a child. I felt like there are 3 adults and 10 kids, why was no one paying attention to him? We felt stuck (with no options) because I had to work and nowhere else to take him. There were only a few more weeks until school started, by the time I had figured it all out we just wanted to make it through until then.

-- FSN_Interview 18

When he attends day care the teachers tell her he is hyperactive. She resents them referring to him in undiagnosed terms and feels they make be saying that because of his race. When interviewing for a new daycare facility she explained his issues. She was told, it looks like he won't be a good fit. Staff would not be able to handle him. They hadn't even meet him yet to evaluated him themselves. Owner's daughter tried to undo what her mother had said but it was too late. She did not take him there. She did not feel he would receive good care.

-- FSN_Interview 21

I wish we would have had more help from the preschool, he wasn't diagnosed then, and it was just that we knew he was difficult. But we could have gotten help sooner instead of just thinking he had bad behavior.

-- FSN_Interview 7

Pre K was the worst mistake we ever done. Teacher was not even certified to deal with a child like my son.

-- FSN_Interview 10

Race did not affect his services, his physical appearance and limitations have. We have declined preschool services since they don't want to challenge him and expect him to succeed and learn.

-- FSN_Interview 38

Elementary schools (K-3rd grade) were supportive for some respondents:

It was a team effort with the school counselor, doctor and social worker sending the person to my house to give me the help I needed.

-- PH_Interview 2

Called the school and set up an appointment. Told them what was wrong and the school helped to provide that service. Thought the school did a good job and accurately solved that problem.

-- PH_Interview 9

The elementary school is extraordinary and supportive. A lot of the terminology used in the culture of the school is really inviting. The environment is conducive to helping socio-emotional children. I feel comfortable and heard there.

-- FSN_Interview 23

There was a time her daughter didn't want to go to school and the guidance counselor helped talk with daughter and then talked to mom to and helped her daughter understand the importance of going to school

-- FSN_Interview 5

The school really looks out for my kids so that is helpful.

-- FSN_Interview 9

Difficulties with elementary schools (K-3rd grade):

At school they delay everything because they assume he does not speak the language. They performed a second test to confirm he did speak the language. After all that, I left [the school district]. I wasn't able to keep him the school I wanted to because [the district] removed us from all the programs, including the lottery, he lost his spot. He did not adapt to the [district] preschool and being there. He played, but at the time to sit down to listen to the teacher he would regress.

-- CBP_Spanish Interview 5

If you were able to homeschool, [child's dad] would. It's easier—could more easily control the social experiences.

-- PH_Interview 4

Wish there was more help at the schools. All they do is tell him he knows better, but he really does not. He then rebels and tears things up.

-- FSN_Interview 20

I wanted him to be more involved with supports at school but his behaviors weren't severe enough when I asked for them. The school wouldn't do testing because he was too smart and not showing educational problems. Then it got really bad and they called me because they had to restrain him so I wish there were earlier supports before things became such a big problem. I think the school felt like I was a "crazy mom" until it happened while he was there. Then it was a problem.

-- FSN_Interview 26

The way they talk to me is very important. I don't really understand English and sometimes it's hard for me to understand and process what I'm being told. I feel sometimes they (school staff) gets frustrated with me because of the language barrier. They have made me feel uncomfortable. I just wish they would be more patient and understanding.

-- FSN_Interview 1

More people to understand what families are going through and help them when they are having a really hard time. Schools could help more with families so that their child isn't left behind and sometimes it doesn't feel like we have enough help.

-- FSN_Interview 36

What I will answer is that neither with the doctor nor with the school I have received any support. At the schools, [we need] people committed to work with the children.

-- FSN_Interview 41_SP

Teachers (child care – 3rd grade) were supportive for some respondents:

He is easily distracted. He is kind of like a class clown—he wants to be the center of attention. He has had a couple of times when he is playing or entertaining another student—his teachers are good at identifying that as well.

-- PH_Interview 1

Teacher: A great one—her first grade teacher loves her! Extra attention, gifts, extra communication with parents. Teacher went above and beyond.

-- PH_Interview 4

Teachers: They notice when things change like if he (my son) misses classes or his behavior changes. I want them to communicate with me. For example, my son was having a hard time concentrating in class so the teacher lets him sit outside to finish his work with her. He was getting overwhelmed in the classroom so he is getting more one on one time with teacher, free from distractions.

-- PH_Interview 6

Even though we are starting online, I feel like we have a good partnership with the school. Sometimes I forget the class meeting, so I forgot the class meeting. The teacher was very understanding, that is the support and the relationship I need. It is not an everyday thing. The teachers have helped me with the stress because when needed to vent out, they have listened, my daughter's teacher right now is really good at listening.

-- PH_Interview 7

The only thing was at school when the teacher said that he wasn't learning like before. But his father told the teacher what had happened and then she was very helpful.

-- CBP_Spanish Interview 8

The EChO program worked closely with the teachers to help them understand strategies – e.g. helping teachers give child reminders. Teachers should be professionals and know how to help different kinds of kids. Teacher suggested behavior therapy – not helpful because she was 3 years old and toddlers just do stuff. You shouldn't talk about kids that way. EChO program was helpful because they helped the teachers.

-- FMF_Family 13

You know a teacher really cares when they call to check on you.

-- FMF_Family 28

The teacher let me go outside and talk to my son personally. She trusted my expertise and she even came by a couple of weeks ago and gave us some house-warming stuff. I'm going to miss her. But he does have a good teacher for his first grade.

-- FMF_Family 29

I will say his teacher [helped]. Because this whole virtual learning thing was to the point where I had to choose between work and my child's education. I would be really, really scared if I had to lose out on my job or if he will not be on time for class. He's not with me. He's with teachers at my school, and they're doing the best they can but they have 15 kids. His classroom teacher told me to let her know if he was not able to log on and she also did pre-recorded [lessons].

I feel like it was helpful to know that she knows that she does care. She didn't know much of what to tell me but she reassured me that we were going to work together to make sure that [child] was going to be okay and do what he was supposed to do.

-- FMF_Family 30

It is all about the communication between the teacher and the parent. Parents need to continue to do what the teachers are telling you to do. With the teacher she has now, she has been very proactive.

-- FMF_Family 5

Having good communication. We had a teacher who would always let me know what was going on with all my children. She taught 3 of my kids. Even now that she doesn't teach them, she still keeps in touch.

-- FSN_Interview 3

Teachers. After he was identified, we sat down and looked at what works best for my son. We all prepared for what to expect to help him. We used a picture schedule we walked him through the schedule ahead of time.

-- FSN_Interview 7

Homeschooling last year was difficult. His teacher really offered options that really help me help him.

-- FSN Interview_30

Difficulties with teachers (child care – 3rd grade)

Teachers and guidance counselors should speak and interact with each student—provide services regularly—not just when it is a big issue. Identify why he was doing those behaviors; asking more questions—instead of automatically labeling it a behavior issue—ask what the child is experiencing outside of school--not just assume they are bad. Teacher did not come to parent; wishes that the teacher came to parent first instead of blowing it up and then reporting to the parent. The teachers said he was problematic vs. trying to help him occupy his time or re-direct.

-- PH_Interview 1

My fourth grader, her teacher doesn't communicate well. My other kids' teachers have good communication. When teachers do communicate they shouldn't just talk about the bad about the child. Praise what they are doing good.

-- PH_Interview 11

I wish the teacher would have went a different way about it. The teacher didn't know the situation. I wish teacher would have asked mom first before giving [the child] solutions (i.e., "Call dad"— well, that is not appropriate in their familial situation).

-- PH_Interview 15

I ask a lot of questions and sometimes teachers and doctors don't want you to ask them questions.

-- CBP_Spanish Interview 4

I hadn't felt anything good with my son's school. Pre-K and K weren't good experiences. In first grade it got better, but it was hard to have good relationships with his teachers. When we arrived [for younger child] at *** Bilingual Preschool, everything changed.

-- CBP_Spanish Interview 7

Teachers should have better training about strategies to work with all types of kids whether they're mentally challenged, disabled, anything.

-- FMF_Family 13

I think that the classroom teacher who spent the most time with her needed better training and support. This was when the school system dropped their extra teacher assistant. There wasn't a TA in the classroom. That TA was stretched extremely thin. It was never enough for one adult to manage. There should have been extra things done.

-- FMF_Family 6

Her current teacher will not work with her when she is nervous or upset. The teacher said "We don't do that here". The teacher does not give her time to process.

-- FSN_Interview 22

Teachers and doctors should have a fundamental understanding of diagnosis. She would have a lot of confidence in them if they had a good understanding.

-- FSN_Interview 23

Providers should have background in child development so they know what is appropriate.

-- FSN_Interview 24

More teachers who understand. You can't always go by the book. Think outside of the box.

-- FSN_Interview 25

The first year of kindergarten was hard because the teachers didn't seem to understand his situation and all the doctor appointments he had. Scheduling around out of town doctor appointment has been very hard and trying to not miss school or therapy appointments and trying to keep a job or have transportation to appointments if I had appointments, myself. Things are getting better. He has wonderful understanding teachers.

-- FSN_Interview 36

The family survey asked about where respondents would like to use services – home, doctor's offices, or school/child care:

	Would you use services at your child's school or child care?	Would you use services through your child's doctor?	Would you use services at your home or where you live?	Number Surveyed
All	60.9%	33.3%	78.3%	138
African-American/Black	61.5%	30.8%	53.8%	13
Latinx (English)	78.6%	50.0%	85.7%	14
Latinx (Spanish)	64.1%	20.5%	79.5%	39
Native American	80.0%	80.0%	60.0%	5
White	53.1%	36.7%	79.6%	49
<50% FPL	52.0%	60.0%	64.0%	25
50-100% FPL	56.3%	28.1%	87.5%	32
100-150% FPL	66.7%	33.3%	86.7%	15
150-200% FPL	57.7%	19.2%	80.8%	26
>200% FPL	80.0%	30.0%	80.0%	10
Male	57.1%	21.4%	71.4%	14

Note: FPL=Federal Poverty Level for a family of 4 in 2020 ($26,200)

Highest number would like services at home (78%). More than half would use services at school/child care (61%), and respondents were less interested in services through doctor (about one-third).

- Race: More than half of respondents in every group are interested in services at school or child care. Native American (3 out of the 5) and Latinx (English) (79%) respondents are the ones most interested in help from school/child care. Black respondents are most interested in services at school, then home, then doctor. Hispanic (both) and white respondents are most interested in services at home, then school, then doctor. Native American respondents are interested in school and doctor, then home.

- Income: Highest income bracket is very interested in services at school/child care, but more than half of every group is.

- Gender: Male responses are similar to the overall responses.

Foster Care

Six foster families were interviewed. Their responses are themed and summarized below. Included at the end of this report are some responses from other interviewees who are not foster families but who have had interactions with the child welfare/foster care system.

Foster parents shared that they themselves, other family members, other children, and professionals like therapists most helped the children in their care learn how to make themselves feel better when they are upset, scared or sad, to talk about their feelings, and to form strong friendships.

Me (the Foster Parent):

If I observe that a child is feeling out of sorts, I try to understand why he/she may be feeling that way. I do a lot of activities with the children, such as gardening, which oftentimes allows for me to engage in conversation with them. I don't push the child to talk but I do create opportunities in conversation for them to open up. Through this means of holding conversations while doing activities of interest with the children, it may take some time but they usually open up very naturally with me how they are feeling.

-- FSN_Interview 11_Foster

Me and my husband would ask the child to pause and take a breath and then try their best to express what they were feeling.

-- FSN_Interview 13_Foster

Given that the children placed with me, as a NHCDSS foster parent, are with me more than anyone, I try my best to help each child feel better when they are upset or troubled. One little girl had a lot of questions about all the different emotions she was dealing with after the trauma of being removed from home and placed in foster care. I let her know if she ever wanted to she could come and ask me which developed into almost an every day experience during part of her bedtime routine.

-- FSN_Interview 14_Foster

My husband (Caucasian) and I (African-American) are both in a second marriage and have adult children. We decided to foster to adopt and have adopted 5 children ages 5-15 each with various special needs. We are very engaged parents and strong advocates for our children and did both self-learning as well as gaining knowledge through our various experiences from the service providers for our children.

-- FSN_Interview 16_Foster

Other family:

Growing up I always had extended family and family friends around and we were always talking about what we were doing, and in so doing, talked how we were feeling too. This same interaction is what I find most natural to use effectively with the foster children I have had.

-- FSN_Interview 11_Foster

Other kids:

We felt the children who have been placed with us all had basic skills to make/keep friends as they demonstrated among the children their age in our neighborhood.

-- FSN_Interview 12_Foster

Since we have a number of children in our neighborhood, we've been able to foster nice friendships for our children among our neighbor's children.

-- FSN_Interview 13_Foster

Therapy:

We've had many children where Intensive In-Home Services were provided so they had a team to help the child calm down and support them, along with services from the Mobile Crisis Unit provided.

Each child we fostered had a mental health therapist in place who for the most part we were satisfied with and had a good rapport with the child and with us. A lot depends on how accurate the initial diagnosis was, if it was later determined to be wrongly diagnosed this created major problems in the care and treatment for the child.

-- FSN_Interview 12_Foster

The services (MH therapy, Intensive In-Home Services) that have been in place. Most of my foster children enjoyed the IIHS workers.

-- FSN_Interview 14_Foster

Some of our foster and later adopted children came to us with paperwork and diagnosis/ services already in place. Two of our children are biological siblings who are now 13 and 15 years old but were 7 and 9 when they came to us. They had a lot of emotional issues with the trauma of being removed from their parents and then their subsequent failure to reunify. We worked closely with the psychologists and therapists to help them through this.

-- FSN_Interview 16_Foster

Child Care/School:

Our son's involvement through the CDC and public school as well as our active family life has helped him the most.

-- FSN_Interview 16_Foster

Foster parents shared that their own families, other foster parents, programs they have been a part of, and doctors have helped them learn how to support the social-emotional health of the children in their care.

Family:

I learned most of my parenting skills from my mother.

-- FSN_Interview 14_Foster

Other families:

Fellow foster parents we interact with.

-- FSN_Interview 12_Foster

We have not encountered difficulties we have not been able to resolve. I am a part of a special needs mothers support group which has been very beneficial.

-- FSN_Interview 16_Foster

We've found good support through the other persons who went through MAPP training with us… We have not run into many situations where we've had to ask for much help beyond what advice or shared experience we hear from other foster parents.

-- FSN_Interview 13_Foster

Programs:

Our foster care agency's training has been helpful, particularly through *** Family Services.

-- FSN_Interview 12_Foster

We've found good support through the other persons who went through MAPP training with us and also the *** County DSS Foster Parent Association monthly training classes.

-- FSN_Interview 13_Foster

Going through MAPP foster parent training and the ongoing monthly foster parent association trainings, I have learned a great deal.

-- FSN_Interview 14_Foster

The Early Intervention Program and the CDC have helped significantly. The staff at CDC made us feel welcome and also the Autism Society has been helpful for us through the years for our son.

-- FSN_Interview 16_Foster

Doctor:

Oftentimes the child's therapist was a sounding board for us and helped explain things.

-- FSN_Interview 12_Foster

Foster parents described what a good partnership between them and the doctors, teachers, or support people in their children's lives would look like and feel like. They highlighted the importance of communication, trust, engagement, and respect for their roles.

Communication:

A relationship where it's safe to raise questions and where there's open communication where progress is shared. Helpful when time is taken to explain when needed.

-- FSN_Interview 13_Foster

It's important in order to have good two-way conversation. It happens when both parties can talk openly.

-- FSN_Interview 14_Foster

Good communication and the ability to ask questions and frequent updates from our children's teachers and/or therapists is important.

-- FSN_Interview 16_Foster

Trust:

Being honest and open with service providers and professionals.

-- FSN_Interview 12_Foster

When I have a question, I want honest talk back.

-- FSN_Interview 14_Foster

Engagement:

This psychologist takes the time to really listen and they come prepared for the child's appointment which shows how engaged they are, up to speed and have read up on the child and/or their special need.

-- FSN_Interview 11_Foster

We and the child really benefit when someone listens and helps direct you to needed services.

-- FSN_Interview 13_Foster

The doctor tells me to calm down and take it easy and spends extra time to really listen and speak with me.

-- FSN_Interview 14_Foster

Respect:

I wish they would have more respect or inclusion for the role I have as the child's primary caregiver.

-- FSN_Interview 11_Foster

Listening to understand and responding respectfully.

-- FSN_Interview 12_Foster

Foster parents shared how the social-emotional challenges of the children in their care were identified. They mostly had the support of professionals to identify these concerns.

Through my own observations or as related to me by the daycare workers or teachers, or when tested by CDSA and then hear of notable deficits/needs.

-- FSN_Interview 11_Foster

We had one child who had been diagnosed at the age of 5 with Reactive Attachment Disorder but the diagnosis was ignored and dropped from the child's records until they were 10 years old. It wasn't until they were committed to Bryn Mawr Hospital and the staff researched old records and discovered this RAD diagnosis which could have helped for all the 5 year time in between. We went through a lot of hurdles to find the correct diagnosis for the child. The staff at their local elementary school, particularly the school counselor, helped a great deal.

-- FSN_Interview 12_Foster

Our local CDSA assessed the sibling pair and got services through Child First in place.

-- FSN_Interview 13_Foster

Through my own observations, I raised any concern to the child's social worker and then their family treatment team put services in place.

-- FSN_Interview 14_Foster

With our son who is diagnosed with autism, it became known through a well child check as an infant that he had significant delays. His pediatrician referred him to UNC Hospital for further evaluations and it was through those assessments that he was diagnosed with autism. The staff at CDC proved to be very beneficial to our son and to us as parents.

-- FSN_Interview 16_Foster

The foster parents were asked:

- Have you ever felt like the way someone thought about your child was affected because they didn't understand your culture or background?
- Has race or the way people feel about race affected you and/or your child's experience in being identified as having trouble managing their feelings or getting along with others or in getting services to address a social-emotional challenge?

These foster parents shared that race had not been a significant issue in their experience.

Not towards me (Jamaican American), but sometimes I've noticed that a particular daycare may not work with a child in my care, so is known to be in foster care, and the daycare is less tolerant of their behaviors. I expressed my concerns to the child's DSS social worker and we moved the child to a different daycare.

-- FSN_Interview 11_Foster

No, race has not been a significant issue in my experience. One Caucasian girl placed with me, an African-American, seemed to develop an affinity to African-American boys her age and initially her step-father felt I was influencing this, but we talked it out and resolved his misunderstanding.

-- FSN_Interview 14_Foster

Because we are a bi-racial couple, we sometimes play the white card (my husband) or the black card (myself) depending on what we are encountering. It does not seem like race has been a significant factor for us in getting services in place for our children.

-- FSN_Interview 16_Foster

Not really as they are Caucasian and have only had Caucasian children placed with them so far.

-- FSN_Interview 12_Foster

The foster parents shared what has made it difficult for them to access programs, services or supports to address the social-emotional development of children in their care in the past or right now. They highlighted obtaining diagnoses, being aware of available services, issues with insurance, the system not centering the needs of the child, communication with providers, and the lack of services, including crisis services and services for bio-parents. One foster parent highlighted the importance of her own advocacy in getting services for the children in her care.

Labeling

I wish it wasn't so hard to get an accurate diagnosis, or especially to get a wrong diagnosis changed.

-- FSN_Interview 12_Foster

Awareness

I wish there was a single portal or agency or place to go for help in dealing with a child's social-emotional challenges. It all seems so vague and difficult to get what you need.

-- FSN_Interview 12_Foster

It is so difficult to find out who provides what services for the child as well as support services for the parents. I wish there was a simple system to disseminate information such as identifying what resources are out there for what needs/services. All these think tanks are great but they are not accessible for me to get through this sea of unknowns.

We've felt mostly "beat up" by the system and how many hurdles there are to know what services are needed and then where/who to access them through.

-- FSN_Interview 12_Foster

Insurance

We'll advocate for the children in our care and really get frustrated especially when a service need is identified and then Trillium denies those services. Medicaid oftentimes it seems get the least experienced service providers.

-- FSN_Interview 12_Foster

Not focused on child

I have difficulty when a child is in the midst of the IEP process and the child-centered plan seems more wrapped around the decisions of the child's bio-parent, who oftentimes does not understand or take the time to understand what their child's special needs are. I feel it is better when there is a person who is more familiar on a day-to-day basis.

-- FSN_Interview 11_Foster

I might be more biased as a foster parent, but I wish agencies and professionals who work with children would be more child focused rather that focused on the parents. It seems the parents' needs are oftentimes put ahead of the children's needs.

-- FSN_Interview 11_Foster

Crisis Services

We wish there was a simpler format or process to assist parents when they are going through a crisis with a child. Sometimes it seems like the professionals have handcuffs on in their inability to help.

-- FSN_Interview 12_Foster

I wish there was a Crisis Line phone number to call for help when dealing with a child's crisis.

-- FSN_Interview 13_Foster

Lack of Communication

More ongoing communication during long-term therapy/treatment.

-- FSN_Interview 13_Foster

Wish that therapists/providers who provide services over a longer period of time would take the time/effort to give updates on the child's progress. I wish we were given more feedback on how the child was progressing every 6 months or so.

-- FSN_Interview 13_Foster

Not enough services for bio-parents

I would like to see more services being provided to the children's biological parents and like it when we can develop a positive shared parenting relationship. Even when children go home they oftentimes call me to speak with me and I like that.

-- FSN_Interview 14_Foster

In my experience, I've had more difficulties in dealing with the social-emotional health of the children's parents than the social-emotional health of the children.

-- FSN_Interview 11_Foster

Advocacy

We've been able to obtain needed services, but it seemed if we had not been such outspoken advocates for our children, we're not sure if our children would have received as much help as they have.

-- FSN_Interview 16_Foster

The foster parents shared comments about the experiences with various sectors of the social-emotional ecosystem, including school, caseworkers, doctors, early intervention, and CCNC/CC4C. They mostly report good experiences, along with some frustration with caseworkers.

School

I've had mostly positive experiences with the school system.

-- FSN_Interview 14_Foster

I'll have to say our participation with our children's IEP teams has been very beneficial for us and our children. We strive to develop close working relationships with all our children's teachers and schools. Good communication and the ability to ask questions and frequent updates from our children's teachers and/or therapists is important.

-- FSN_Interview 16_Foster

Caseworkers

I get frustrated when I've shared a concern with a child's social worker and they don't call back or respond and seem negligent to get a service in place. Something else that occurs too often is when a new child is placed with me, I rarely get adequate information from the social worker.

When I feel that a child's issues are beyond my skill level, I pass on my concerns to the child's social worker to get services in place.

-- FSN_Interview 14_Foster

They may say the child needs speech therapy but they are slow or negligent in getting it in place

-- FSN_Interview 11_Foster

Sometimes our agency worker would be very supportive in listening and responding to our needs for the child.

-- FSN_Interview 12_Foster

The Child First worker was helpful who met with us prior to her time with the children and then following before she left.

-- FSN_Interview 13_Foster

Pediatrician/other doctors

There is this one particular child psychologist whom I have a lot of respect for.

-- FSN_Interview 11_Foster

We came upon this excellent child psychiatrist at ***

-- FSN_Interview 12_Foster

We've had good experience with some of the pediatricians for the children placed with us.

-- FSN_Interview 13_Foster

Once a pediatrician told me to call him whenever I felt it was needed, that meant a lot.

-- FSN_Interview 14_Foster

Early Intervention

We've only dealt with CDSA and Child First which were positive experiences for the most part.

-- FSN_Interview 13_Foster

The Early Intervention Program and the CDC have helped significantly. Our first foster-adopted son, diagnosed with Autism, was enrolled in the Child Development Center (CDC) and that proved to be a good experience overall for his social-emotional development. He was non-verbal for much of his early years.

We wish in addition to the social-emotional focus at CDC that there would have been additional focus on pre-academic skills to help him be more prepared for public school.

-- FSN_Interview 16_Foster

CCNC/CC4C

I wish I was provided with more information about the child when they are placed with me. I oftentimes feel like I'm going in blind. A number of times my experience with CC4C workers have been challenging, in that it feels like I'm pulling teeth to try to get information which will be helpful for me as the primary caregiver.

I've had some good experiences with CC4C workers as well. One CC4C worker nominated me as a Champion for Children for the annual Smart Start Breakfast.

-- FSN_Interview 11_Foster

Some birth parents shared their experiences interacting with the child welfare system. They also report frustration with caseworkers.

Once a caseworker came to my house because I didn't think I could handle it.

-- PH_Interview 2

Currently, we are working with CPS caseworker. So our child has learned about feelings from the case worker as well. They (Social Services) have helped me with everything that I have asked for.

-- PH_Interview 15

There are differences in case workers. Some caseworkers don't treat you equally. Some provide better services than others.

-- PH_Interview 11

Sometimes social workers are helpful and want to listen and sometimes they don't know what they are talking about or what is available. A lot of the service workers are stressed and overworked because so many people are having trouble with housing etc.

-- PH_Interview 3

They need to be more concerned, and not just doing a job. If the person cares, she can make a difference in our life. Unfortunately, I have gotten 2 case managers who were very unconcerned. When the job was up, it wasn't about us anymore. Just a little more caring, more concerned.

-- PH_Interview 8

Our story is a little different. We went to CDSA from DSS. My son had a fracture and they put him in foster care and they put him in CDSA because he was premature. As far as our situation what I wish would have been different is that the CDSA workers that were coming out (were saying) well if he wasn't fractured this wouldn't have happened or if he wasn't fractured he would have the leg strength to stand up, and I had to go loopholes to prove that wrong. I just wish it would have come out that it wasn't an abuse situation. It was a complete and utter accident, so I guess the whole time I felt like the case worker was not understanding or making assumptions. Up until last year his case worker called my kids' dad the abuser and their dad. It took me finally saying: he did not abuse our children, do not say that anymore.

-- PH_Interview 8

Ecosystem Supports

More things that fill the gaps, systemic programs. The system needs to change. You should not need a doctor's referral. Should be able to request an appointment without one. Perhaps a simple screening to see if they meet criteria. There should be more emphasis on early childhood years. Parents would like personal connections. Need programs that are available to anyone in need, not just those on Medic[aid] or who can afford the cost. There need to be improved options. There needs to be a focus on attachment in early childhood. Should be an emphasis on improving the children and family lives. Holistic care. More services, accessible for everyone. Services need to have competent and trained professionals working with the children. Streamline the process for obtaining services.

-- FSN_Interview 24

The old adage about the squeaky wheel. She had to get help, but no one could tell her where to go for it. No one dealt with children under the age of five. It was a very frustrating experience. HIPPA created one more barrier for a parent begging for someone to help her because no one knew what the other person was doing. Parents are left hanging. If she and her husband had not imploded, they would not have received help and services. You must be either loaded or butt broke to get help! There need to be services for the entire family because it effects everyone.

-- FSN_Interview 28

I signed up for WIC and child support services. When my son was young, I feel like there could have been someone early on at that time to do testing with him. We didn't get a diagnosis until he was 5, but I was on WIC and all kinds of support so I feel like the welfare program could have been used as an evaluation time, like actually evaluate the kid. It's more about 'oh here is your check,' but no real care about making sure your kid is where they need to be. It's like they want to make sure they're fed but they don't care if, you know, if the kid falls through the cracks. I don't know how early intervention could have helped with that, but I'm thinking that if you're getting support from social services, they could help more – give us more information and communication about services so we don't fall through the cracks.

-- FSN_Interview 7

People who have the jobs to help (the agencies), they've been dropping the ball all around the table. Usually the good people are the ones who don't have the ability to make the decisions; due to policy/procedures they can't get much done.

-- PH_Interview 5

Family members want good communication among providers and collaborative care:

We got bounced around in different counties to try and get resources and there wasn't communication between counties.

-- PH_Interview 11

Sometimes it seems like things are so spread out and not connected. Sometimes it is hard for big agencies to communicate with each other. Sometimes you go to one person at an agency, and go to another place and you go to so many people and share the same story.

-- PH_Interview 7

The evaluation is just one day. They should listen more to the people who are around the kids every day – like teachers and parents. I think he needed more help with his behavior. Because they didn't see it on that one day for 30 minutes, they didn't approve that help. They need to do more observations and/or listen to parents and teachers more.

-- FMF_Family 7

Collaborative care. You have to repeat yourself everywhere you go, School needs, doctor's needs, etc. One care team approach. Everyone knows what part they play in the care process, explain what each provider covers, to achieve positive results for the child. They need to be open hear what parents and other providers are saying not just what "they do". There are lots of gaps. I wish we could fill them in with a more collaborative approach and partnerships. Everyone needs to know about each role and work together.

-- FSN_Interview 22

I would love for there to be more support in terms of an integrated work between the community, home and institution. A comprehensive collaboration in which needs can be identified and worked on. First that parents receive orientation of existing services, accessibility and uniformity including the integration of the services that the child receives. Understand how services work, how to use them. And within the socio-emotional services they will provide orientations to people who provide public services to the community such as firefighters, police, etc.

-- FSN_Interview 40_SP

Accessibility: more streamlined processes, better timelines for getting services:

The experience has been useless, because my child would have made more and many progress. Many of the difficulties would have been avoided if all supports had been delivered on time.

-- FSN_Interview 41_SP

We need more resources and services for parents. We lived in other states before and they offer far more services.

-- FSN_Interview 20

They moved out of the State for two years. The community had a system where a child with a diagnosis was provided low-cost services, preschool, supplies and other needs. Funding was in place and there were lots of options.

-- FSN_Interview 23

More streamlined processes to get behavioral supports. To get my son to see a psychologist, I had to go through lots of steps including getting a letter from the pediatrician.

-- PH_Interview 6

I would say we can get all these bandage programs that heal our wounds for the time-being and not long term. It’s like kids actually have to be out cold on the street. I feel like it shouldn’t need to get that far before someone says okay you are actually homeless now.

-- PH_Interview 8

It was not easy to obtain services/resources when we recognized the need. Before she had the same doctor for her whole life. When we arrived here we had a new pediatrician who did things differently. She was going to refer us to Community Care of North Carolina. I talked to the nurse but she didn’t do it. They never came to do the evaluation and when we talked to them the nurse said that everything was fine. Later they sent a letter saying that we were no longer going to receive the services, even though we had never received anything to begin with. I had to keep calling and searching services for over a year. They didn’t refer us. When we went back to see the doctor, she told me to register in a pre-kindergarten program and do an evaluation. They assessed her and I had to send many, many documents to register. The processes here are terrible and take forever. This month is one evaluation. The next month another evaluation. and so on and you wait 3 months or more to even begin services.

-- CBP_Spanish Interview 6

Being connected to a service initially was hard. Offering services - more immediate appointments - disappointed with the timing and how long it takes to get things started.

-- FSN_Interview 21

I wanted him to be more involved with supports at school but his behaviors weren't severe enough when I asked for them. Then it got really bad and they called me because they had to restrain him so I wish there were earlier supports before things became such a big problem.

The cost, wait time and lack of providers here was hard. I would make it easier to get evaluated and make it more affordable. More access to preventative and early services. More education to pediatricians and preschool teachers on what to look for in those smaller signs. Resources that are easy for parents to find.

-- FSN_Interview 26

I have had good and bad experiences. Some services have been difficult to get. I have looked in the community to see what kind of services they offer. Nobody is going to told me where I could go get the services for my kids. There are other counties that offer the services you cannot find in your county and if there are, you're put on a waiting list. I would like my kids to have the Home Skill service, but because he doesn't have a waiver, he cannot have it.

-- FSN_Interview 40_SP

Not taking into account what a person has available in order to utilize resources: Sometimes they don't ask if we have the resources to even eat the food we give. Like if I don't have a can opener, I can't open the cans. Or if you are living in a car you can't heat up frozen goods. They need listen and understand and not just give you free stuff that goes to waste. Having to jump through hoops to get resources: Having to go to multiple agencies to meet one need.

-- PH_Interview 3

Navigators:

I wish there was a single portal or agency or place to go for help in dealing with a child's social-emotional challenges. It all seems so vague and difficult to get what you need.

-- FSN_Interview 12_Foster

Q: Is there anything you wish would have happened differently?
A: That I didn't have to go all over the place, from one place to another.

Focus more on educating parents, to give them greater awareness and knowledge of the supports and the system. The hospital gives you a book and tells you how to manage things day-to-day but they don't guide you or talk to you about how the system works. You have to choose a pediatrician alone, no one helps you. You aren't born knowing all of these things and knowing how to be a parent. You also have these barriers in the system that aren't clear. You don't know what resources exist, when you can receive them or when your children can receive them. I don't know anyone. I don't have anyone who can help with childcare. It makes me anxious to leave them with someone. You need to work and there aren't resources, instead there are barriers.

-- CBP_Spanish Interview 2

When a child ages out of one program there should be another one for them to advance to. Problems don't stop. You got to start all over again with something new. Trying to enter the program - getting an appointment took months on a waiting list for a doctor. Closest doctor was a long way away and hard to get to. Not being told it would be such a long process. Then once they made the diagnosis they didn't see them anymore and I had to figure out who was going to help next. COVID, not getting therapy in person, child did not do well with the therapist on line, couldn't handle it. There was negative change when tried to do it online.

-- FSN_Interview 25

More people to understand what families are going through and help them when they are having a really hard time. Schools could help more with families so that their child isn't left behind and sometimes it doesn't feel like we have enough help.

-- FSN_Interview 36

A better understanding of what's available and help with filling out applications.

-- FSN_EngSurv27

There should be a service that is NOT provided through the school system, that doesn't have an obligation to the school system, that works just for the families who can come to these IEP meetings that know how to articulate the needs of the child and who knows how to hold the school accountable to provide these services. There should be either a person that can provide these services for families or there should be a classroom-like setting or training that trains the parents to know IEPs and requirements and obligations so that we can be the best advocate for our children.

-- FSN_EngSurv58

Clear information about navigating the services. I regularly hear about services other families have accessed but can't seem to find the necessary information/agency/person to get that service for my child.

-- FSN_EngSurv60

It would be good if someone could visit us (the parents) and guide us on how to educate our children so we are all on the same page and we know what is happening.

-- FSN_SpSurv6

APPENDIX A: Family Voice Survey

Thank you for agreeing to take this survey and share some of the wisdom you have gained through raising your child. We really appreciate your time.

The purpose of the survey is to learn what is working well, what is hard for families, and what would help families to support their children's social-emotional health and development. Parent/caregiver input through this survey will help us to better understand and work towards a strong, fair, easy to access system that helps all children develop healthy social and emotional skills, so that they can have friends, be happy, do well at home and in school, and become successful adults.

"Healthy social-emotional development" is the ability for young children to have close relationships with their families and friends; to understand the feelings of others and manage their own feelings and behavior; and to feel safe and comfortable while they explore and learn. We know that if children are able to do these things when they are very young, they can be successful at home and in school.

In NC, there are several programs and systems that help children develop their social and emotional skills, like early intervention (CDSA, CMARC), doctors who deal with concerns about young children's social-emotional health (like behavior and how the child gets along with others), home visiting, parenting education, Medicaid, child care and your child's school.

The people trying to make sure that those programs and systems work well need parents' voices and expertise to make the system work for ALL North Carolina's children. It is especially important for them to hear from diverse families whose voices have frequently been left out of these conversations, in particular Black, Native, Latinx, and People of Color, people living with poverty, and families with children with special health care needs and disabilities.

So this survey will gather information about your experiences with various programs and systems in order to improve services and supports for families across the state.

There are no right or wrong answers because every family's experience is different. Your answers are anonymous so there is no way to connect your answers back to you.

Please note to what extent you agree with the following statements. For each statement, please check "Strongly disagree," "Disagree," "Agree," or "Strongly Agree."

Question	Strongly Disagree	Disagree	Agree	Strongly Agree
It is important to me that services I access for my child are close to my home.				
It is important to me that transportation is available for me to access services for my child.				
It is important to me that services for my child are provided in my home or where I live.				
It is important to me that I receive services for my child from someone who speaks my first language.				
It is important to me that I receive services for my child from someone who is of the same race as my child and/or me.				
It is important to me that I receive services for my child from someone who values my experiences and opinions.				
It is important to me that I receive services for my child from someone or an agency that makes us feel welcomed.				
It is important for our family to be given choices about my child's services.				

What else is important to you about accessing social-emotional health and development services for your child?

Please choose which of the following services you would use to help you learn how to support your child to learn how to name and manage their feelings and make friends, especially if they didn't cost too much? Please check all that apply.

- ☐ Someone to visit you and provide information
- ☐ A parenting class
- ☐ Information online
- ☐ A pamphlet or an app
- ☐ Services for you if you need help with anxiety or depression

Comments:

Where would you like to use services to help your child learn to name their feelings such as sadness or anxiety, learn what to do with their feelings, and make friends? Please check all that apply

- ☐ At your child's school or child care
- ☐ Through your child's doctor
- ☐ At your home

Comments:

Raising a child can be stressful, exhausting, and frustrating. What services would help you deal with the stress or frustration related to parenting?

Which of the following have made it hard for you to get social-emotional health and development services for your child(ren)? Please check all that apply:

- ☐ I haven't heard about these services.
- ☐ I don't believe my child needs these services.
- ☐ I did not have transportation to take my child to or from these services.
- ☐ The service was not provided at a time of day my child and I could go.
- ☐ The services my child needs are not available in my first language.
- ☐ I do not trust the providers of social-emotional health and development services that I have access to.
- ☐ I did not feel welcome when I took my child to a service.
- ☐ I was not given an opportunity to share my concerns about my child's social-emotional health and development with the doctor, teacher or other service provider.
- ☐ I did not feel supported when I shared my concerns with the doctor, teacher or other service provider.
- ☐ I was overwhelmed by the amount of information I received when I shared my concerns with the doctor, teacher or other service provider.
- ☐ I was not offered services that fit our family's culture or lifestyle.
- ☐ Getting these services for my child is against my cultural or religious beliefs or values.
- ☐ I did not feel my concerns, ideas, and goals for my child were taken seriously when I took my child to a service.
- ☐ Racism and/or racial discrimination have prevented me from accessing these services my child needs.
- ☐ I did not feel the service provider recognized and appreciated my child's strengths.
- ☐ I felt embarrassed about using services that could support my child's social-emotional health and development.
- ☐ I was afraid that if I shared my real concerns about my child's social-emotional needs that my child would be labeled.
- ☐ I was afraid if I shared concerns about my child the provider would think my child's problems were my fault.
- ☐ I was worried if I didn't agree with and do what the doctor or person providing my child's services told me to do I would get in trouble.
- ☐ I was afraid to access the service because I was worried about legal consequences.
- ☐ I don't understand the rules about how to get services.
- ☐ I was worried about rules or obligations that they would want me to follow if I participated in the program.
- ☐ I don't have the money to get these services.
- ☐ My insurance won't pay for these services.
- ☐ I was told I or my child didn't qualify for some services, and I didn't know what I could do to get them.
- ☐ My child received a service, but then I did not receive a follow up appointment or a referral for additional services.
- ☐ I received a referral for a follow up or an additional service, but I was not able to or decided not to access it.
- ☐ I received a referral for a follow up or an additional service, but the other program did not follow up with me.
- ☐ I received a referral for a follow up but the times of day for that follow up did not work for me.

What other barriers or challenges have you run into in trying to get your child the social-emotional health and development services he/she needs?

If you could wave a magic wand, what is something that should be changed or fixed about the early childhood social-emotional health system?

Are you comfortable sharing how you identify your gender and race, your income, and which NC county you are currently living in? We ask because we know that inequities exist among races, income levels and zip codes, so this information would be helpful to fix problems with the early childhood social-emotional health system.

Race:

Gender:

County where you are currently living:

Age(s) of your child(ren):

Estimated Income per week or per year:

Appendix B: Family Voice Interview

Name of Interviewer: _____

Organization: _____ Date of Interview: _____

Introduction

Thank you for agreeing to do this interview today. We really appreciate your time – this will probably take about 45 minutes.

The purpose of our conversation is for me to learn what is working well, what is hard for families, and what would help families to support their children's social-emotional health and development. Parent/caregiver input through this survey will help us to better understand and work towards a strong, fair, easy to access system that helps all children develop healthy social and emotional skills, so that they can have friends, be happy, do well at home and in school, and become successful adults.

"Healthy social-emotional development" is the ability for young children to have close relationships with their families and friends; to understand the feelings of others and manage their own feelings and behavior; and to feel safe and comfortable while they explore and learn. We know that if children are able to do these things when they are very young, they can be successful at home and in school. In NC, there are several programs and systems that help children develop their social and emotional skills, like early intervention (CDSA, CMARC), doctors who deal with concerns about young children's social-emotional health (like behavior and how the child gets along with others), home visiting, parenting education, Medicaid, child care and your child's school. The people trying to make sure that those programs and systems work well need parents' voices and expertise to make the system work for ALL North Carolina's children. It is especially important for them to hear from diverse families whose voices have frequently been left out of these conversations, in particular Black, Native, Latinx, and People of Color, people living with poverty, and families with children with special health care needs and disabilities.

So, I am helping to gather information from families about your experiences with various programs and systems to improve services and supports for families across the state.

There are no right or wrong answers because every family's experience is different. Everything you say will be kept confidential and there will be no way to connect you with your answers to the questions that I'll be asking.

Also, if there are any questions that you feel uncomfortable answering, you do not have to answer them. You can simply tell me that you would rather not answer, and we can move on to the next question. You can also tell me if you would like to take a break or if you need to stop and that is completely okay.

What questions do you have before we begin?

I will be taking notes and I'll also record the interview in case I miss something in my written notes. The recording will be permanently erased as soon as I check the accuracy of my notes. Is this ok with you? *[If the parent does not want to be taped, do not record the interview]*

Interview Questions	Note-Taking
1. Who or what has helped your child or children learn how to make themselves feel better when they are upset, scared or sad? *(pause before and after each question and invite the interviewee to answer)* a. Who or what has taught your child or children how to talk about their feelings? b. Who or what has helped your child or children learn to form strong friendships?	1. 1a. 1b.
2. Who or what has helped you as a parent or family member learn how to support your child's social-emotional health?	2.
3. What types of programs, services, or supports do you wish were available and easy to get to help you support your child's social-emotional development?	3.
4. It is normal for children to experience some social-emotional challenges. Can you tell me about a social-emotional challenge that your child has experienced? *(pause before and after each question and invite the interviewee to answer)* a. How did you identify or learn about that challenge? b. Did anyone help you identify or better understand that challenge? What was that like? Was it helpful? Why or why not? c. Is there anything you wish would have happened differently? d. Can you tell me about your experience with getting services and supports to help you and your child once a need was identified? What did you like about this experience? What was difficult? Would you change anything?	4. 4a. 4b. 4c. 4d.

5. Have you ever felt like the way someone thought about your child was affected because they didn't understand your culture or background? If so, can you tell me about that?	5.
6. Has race or the way people feel about race affected you and/or your child's experience in being identified as having trouble managing their feelings or getting along with others or in getting services to address a social-emotional challenge? If so, can you tell me about that? *(pause before asking next question and invite interviewee to respond)* a. How did that experience affect your engagement with those services? Did you continue using those services or participating in those programs?	6. 6a.
7. Can you describe a time you felt welcomed, understood, or valued by someone who helped your family? What made you feel welcomed, understood, or valued? *(pause before asking next question and invite interviewee to respond)* a. How important is it to feel understood by the people helping you and your child for you to receive the feedback offered, or does it not matter one way or the other?	7. 7a.
8. What would a good partnership between you and your child's doctor, teacher, or support person look like and feel like?	8.
9. What things have made it difficult for you to access programs, services or supports for your child's social-emotional development in the past or right now?	9.
10. Raising a child can be stressful, exhausting, and frustrating. Can you describe a time when your child's doctor, teacher, or support person	10.

helped you deal with stress or frustration related to parenting? *(pause before and after each question and invite the interviewee to answer)* a. What made that experience helpful or unhelpful? b. What would be your ideal experience of support for yourself?	10a. 10b.
11. Is there anything that you would like to add about your experience with social-emotional health programs, services or supports?	11.
12. If you could wave a magic wand, what is something that should be changed or fixed about the early childhood social-emotional health system?	12.
13. Are you comfortable sharing how you identify your gender and race, your income, and which NC county you are currently living in? We ask because we know that inequities exist among races, income levels and zip codes, so this information would be helpful to fix problems with the early childhood social-emotional health system. *(If they are comfortable, please record their responses. Race should be recorded however they choose to identify themselves.)*	13. Race: Gender: County: Age(s) of your child(ren): Estimated Income per week or per year:
Closing Thank you so much for speaking with me today. Have a great day!	