

FRANCISCAN HELPS FAMILIES CONNECT PCORI PARENT ENGAGEMENT PROJECT

SUMMARY OF RESULTS OF SURVEY 3

We are grateful to the **81 parents** who completed Survey #3 and shared very important information about caring for their children with complex healthcare needs. 55% of the survey participants were from throughout Massachusetts representing different healthcare systems; the remaining 45% were from other U.S. states.

Survey #4 will tackle the very important issues that parents face when dealing with their child's insurance providers, getting their child's medical supplies or home nursing support.

Please complete survey # 4 - it will be emailed to you November 30th.

If you know other parents who would like to join, please send them the link below. Parents can join the project at any time - you don't have to complete all of the surveys to participate!

www.franciscanhospital.org/FHFC

TABLE OF CONTENTS

How Does Summertime Change Daily Living for Medically Challenged Children?	1
How Does Having a Sibling with Medical Challenges Affect Typical Children?	3
How Does Having a Child with Medical Challenges Affect Your Relationships?	8
How Does Having a Child with Medical Challenges Affect Your Community Involvement?	12
What Parents Want their Child’s Doctors and Medical Specialists to Know	16

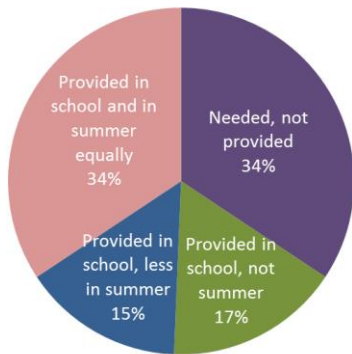
CONFIDENTIALITY STATEMENT

The results contained in this summary are confidential and cannot be used in presentation or publications without the permission of the investigators. For permission, please email cnash@fhfc.org.

HOW DOES SUMMERTIME CHANGE DAILY LIVING FOR MEDICALLY CHALLENGED CHILDREN?

THERE WERE FEWER SCHOOL-BASED SERVICES PROVIDED DURING THE SUMMER.

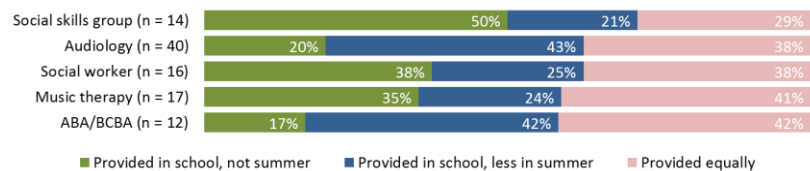
Are school-based services being provided during summer?
(51 parents reported on 306 services.)



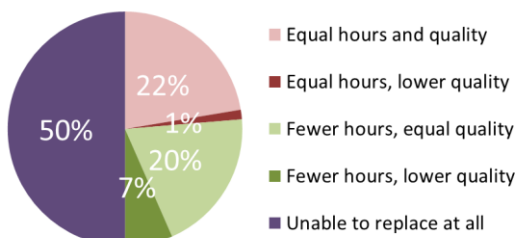
“It is a shorter day so I have to work harder at **finding things for him to do**. It could be used to make gains with him but the school only uses it to keep him at the same level so no gains are made. He is learning more during the school year than he is during the summer. I do not find it especially helpful but **he needs to do something** for his education or he would be even further behind, I have to find things to do that help educate him more because of this.”

“My son benefits from outside therapy more than the limited therapy he gets during the school year.”

Which services are more likely to decline in the summer?



Are parents able to replace reduced services on their own?
(Parents reported on 78 services.)

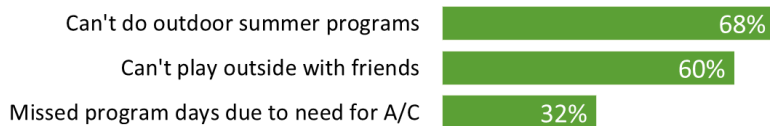


“My child has to qualify for summer service. Basically only evident regression is how summer service is provided. The need of services to maintain present levels is not enough to qualify. **The summer services are hardly minimal.** The sessions become more like a 'check in' than actual work toward goals and objectives. Basically **my child regresses** during the summer with or without school services.”

HOT SUMMER DAYS

60 parents reported that excessive heat negatively impacted their child's health. This prevented their child from participating in outdoor summer programs and playing outside with friends.

What do kids with heat issues miss out on?

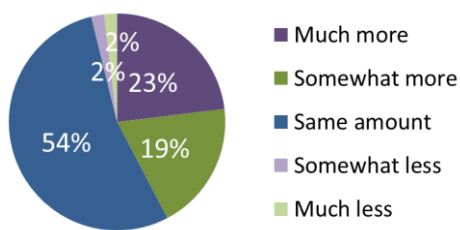


“My child spends **time inside alone** while we are outside.”

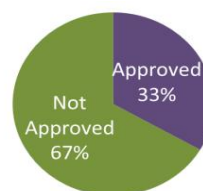
GETTING HOMECARE SERVICES DURING THE SUMMER

Many children needed more home care during the summer, but increases were typically not approved. Some parents also noted that home care staff missed more work in the summer.

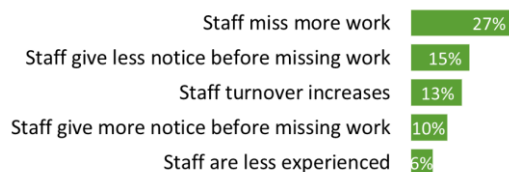
Do kids need more or less home care during the summer?
(52 parents reported.)



When kids need more home care, is coverage approved?
(21 parents reported.)



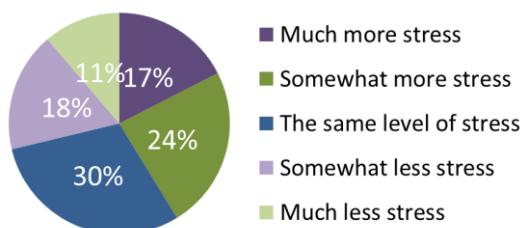
How is home care scheduling and quality different in the summer, compared to during the school year?
(52 parents reported.)



SUMMER STRESS

Parents were more likely to experience an increase in stress during the summer.

Are parents feeling more or less stress during summer?
(80 parents reported.)



“Due to the fact that the school district does not provide a sufficient educational program for my son through the summer, there is **less stress related to school** (making sure they are following through with IEP services & goals) and day to day challenges that arise when school is in session.”

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT TYPICAL CHILDREN?

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT YOUR TYPICAL CHILDREN'S RELATIONSHIPS WITH YOU?

POSITIVE EFFECTS

"It has strengthened our relationship because we really focus on our older children when we are with them. It makes **the quality of our time** more important."

"Parents find typically developing younger sibling to be a **source of joy** rather than stress."

"Parents are **home more** often than if there wasn't a child with complex care needs."

"We are **much more open** about difficult topics."

NEGATIVE EFFECTS

"The youngest needed so much more from me that I felt as though I 'lost' my other 2 in the process, **not as close to them** as could/would have been had this child not had so many issues."

"My child with special needs takes up the bulk of my energy, time and money. I feel like my younger **child gets short changed** sometimes."

"There are times when the affected child's limitations may limit the younger child's opportunities for playdates or other activities, and this causes us a **moment of grief and sadness**."

PARENT ADVICE FOR SUPPORTING RELATIONSHIPS BETWEEN THE PARENT AND TYPICAL CHILD

Speaking one on one to another brother of a child with the same type of needs would be helpful.

*I have worked hard to have them placed in school and with outside help that addresses their needs. This way there **are more adults to reach out to**.*

In our family we have open discussions about the feelings that our older children have. We listen to them and try to explain things so they understand better. We allow them to feel whatever it is they are feeling and then try to find ways to deal with those feelings.

Reminders of full support for younger child's concerns and needs. Open and truthful answers to big concerns. Carving out different kinds of time and activities for each sibling. With young adult sibs, it is sometimes just making eggs together in the morning or chores.

I spoke with her and when that wasn't enough anymore, I had her see a therapist. Also, with the help of the ARC, I got my older daughter a Big Sister.

Usually [respond to resentment] by just apologizing and trying to make time just for her.

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT TYPICAL CHILDREN'S SIBLING RELATIONSHIPS?

POSITIVE EFFECTS

"He's incredibly empathetic and caring. He has lots of patience and tolerance. He is learning that **we all have different strengths and challenges.**"

"They have a special relationship with each other because **they can relate to each other's feelings.**"

"Their relationship with their younger sibling is normal. They **don't treat her like a sick child** they treat her like they would if she never became sick."

"His emotional/behavioral age is similar to his brother's true age so **they have a lot in common.** They are more compassionate and caring than others their age."

"She is kinder as a result, **more understanding,** there's no sibling rivalry, and is really big on telling everyone about her brother. She says he teaches us all kinds of things, and he **'means more than a toy to me. He's the best kid in the world!'**"

"Younger sibling learns that **each member of the family has needs** beyond their own."

NEGATIVE EFFECTS

"My older child cannot share her experiences with her younger sister like most others can. She can also never ask her for advice or help and is, in that respect, **more like a single child.**"

"Older **sibling sometimes annoyed** because he believes younger sibling isn't trying hard enough to be more functional or is exaggerating pain."

"Older sibling sometimes **may not act in the role of older sibling** due to medical issues or developmental delays. This may be confusing to younger sibling."

"They know they have a sibling, yet missed out on the joys of having a sibling...sharing, playing...etc. The younger one **never got to be the baby** in the house because the older one always needed more attention and care."

"Younger **siblings can resent challenged sibling** for causing problems among all family members when things are hectic and also for holding back their lives."

PARENT ADVICE ON SUPPORTING RELATIONSHIPS BETWEEN THE SIBLINGS

Easier access to sib shops might be helpful. Having hospital social workers/staff talk about sibling issues.

We try to engage them both in all activities and reward them both when they do positive things for each other.

Explain, explain, and explain without blaming older sibling. It's a very delicate balance. Distracting younger sibling with a preferred activity when older sibling is having a tough time seems to help mitigate the impact.

We allow them to have these feelings [of resentment] and talk about them. We try to help them see that it is not their sibling's fault that they are sick and we find out what might make things better.

We try to be compassionate and understanding of her feelings while still telling her it isn't okay to resent her brother. If he had the choice, he would not have any special needs and his life is the hardest even though we may all struggle.

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT TYPICAL CHILDREN'S FRIENDSHIPS?

POSITIVE EFFECTS

"She is **more compassionate** with her friends."

"She is more tuned to people who are more empathetic and can accept her younger sister's challenges and thus hopefully ends up **picking better friends.**"

"My younger son is one of the **most compassionate and kindest** six-year-old boys I know. He is very considerate of his friends."

NEGATIVE EFFECTS

"**Pretty much a loner** and doesn't bring friends home into our environment."

"The older sibling may gravitate to radical "fun" **friends who may engage in dangerous behavior.**"

"Play dates can be difficult for the younger sibling due to older sibling's behavior. Also, so much of the schedule can be dictated by appointments that **not much time is left for play dates.**"

PARENT ADVICE ON SUPPORTING THESE FRIENDSHIPS

We explain the situation to the friends and that often allows us to build a deeper relationship with that family.

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT TYPICAL CHILDREN'S SELF-ESTEEM?

POSITIVE EFFECTS

"I think older sibling is learning to feel good about what his strengths are and understanding the importance of **being kind, gentle to oneself.**"

"They are more confident because they see what their sibling is going through and they stand up for her. They have a **thicker skin than most.**"

NEGATIVE EFFECTS

"**Conflicting feelings** of loving his brother and understanding he has special needs BUT still has typical feelings - annoyed, frustrated, angry, and jealous."

"Limited opportunities for socialization have made her **somewhat socially awkward.** She finds it hard to relate to people of her own age."

PARENT ADVICE ON SUPPORTING TYPICAL CHILDREN'S SELF-ESTEEM

We explain that we are each unique creatures, and that the medical equipment is part of the older child's necessities, and she has her own necessities.

Having the medical system talk more about sibling issues.

Providing more opportunities for socialization for families.

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT TYPICAL CHILDREN'S HOME BEHAVIOR?

POSITIVE EFFECTS

"He is **aware of others in the home**. PCA's, therapists, etc., so he does not act out."

"They are **more responsible** at a much younger age and learn to do things around the house to help out. Also **learn to adjust** to new and changing circumstances."

"**More patient, kinder**, more helpful, does things to help without asking."

NEGATIVE EFFECTS

"He sometimes acts out to get attention. Sometimes **says he is sick to get attention**."

"She sometimes **gets away with more** because we try to compensate for her feeling like she doesn't get as much attention."

"They **act out for attention** and ask for medical equipment."

PARENT ADVICE ON SUPPORTING TYPICAL CHILDREN'S HOME BEHAVIOR

We punish them equally.

I had her see a therapist.

Spend one on one time with both siblings individually so each feels special.

HOW DOES HAVING A SIBLING WITH MEDICAL CHALLENGES AFFECT TYPICAL CHILDREN'S SCHOOL BEHAVIOR?

POSITIVE EFFECTS

"They have more empathy and understanding for all kids and adults with special needs and **make efforts to reach out** to them."

"Kinder, **concerned with others feelings**, defends other kids."

NEGATIVE EFFECTS

"He can be preoccupied and **concerned when his complex sibling is hospitalized** and really doesn't want to know about it."

"They do not attend a 'normal' public school and **might miss out** on some school experience."

PARENT ADVICE ON SUPPORTING TYPICAL CHILDREN'S SCHOOL BEHAVIOR

Talk with the school teachers and therapists to let them know what home is like. Clue them in.

We attend field trips and school activities as often as possible.

We worked with the school social worker.

WHAT ARE TYPICAL CHILDREN’S UNIQUE NEEDS?

NEEDS THAT ARE DIFFICULT TO MEET

- “Their socialization needs when they are young.”
- “Time. Attention. Anything we used to enjoy together I am too exhausted to do.”
- “Time, recreation, friends.”

NEEDS AS A RESULT OF HAVING A SIBLING WITH COMPLEX HEALTHCARE NEEDS

- “I wish he had some connections to other siblings who have a sibling with complex healthcare needs.”
- “I think they need alone time with their parents and I think they need to be able to speak freely without thinking they might get in trouble for saying something negative.”
- “Anxiety meds, stress release.”
- “Reassurance that her brother will be ok when he's sick or had a seizure.”

WHERE DO YOU TURN TO FOR HELP WITH YOUR TYPICAL CHILD?

Some parents did not turn to anyone for help if their typical child had issues related to having a sibling with complex healthcare needs. A few parents relied on the typical child’s primary care doctor or mental health therapist. (50 parents reported.)



OTHER SUPPORT

“I talk with my husband and other family members and friends.”

“Other parents in similar situations and/or the 'feelings teacher' at school (elementary).”

“The medically complex child's PT, OT and ST are all very helpful in including the younger siblings.”

“The parents' mental health therapist, other parents, other parents of children with special needs.”

DESIRED SUPPORT

“Would love connections with other siblings, would love help in talking about death.”

“Counseling services to help the older child understand why the rules are different and I expect from both of them only the most they can each give.”

“Support groups of similar families.”

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR RELATIONSHIPS?

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR RELATIONSHIP WITH YOUR SPOUSES/PARTNER?

POSITIVE EFFECTS

“It causes us to **grow together in our religious faith**. It causes us to examine our priorities closely, and make choices about where and how to spend our money, and our time in ways **that ultimately make us happier and more fulfilled.**”

“We are both devoted to our son & want happiness and optimal health for him. We are working toward same goal and **serve as the strongest support to one another**. We are reminded to be grateful for our family.”

“We have learned to appreciate each other's strengths. We support and encourage each other. **We have bonded over a difficult situation.**”

“We have spent the years communicating more with each other and **building an unbreakable trust** through the work and diligence required to care for our child.”

“We really have become best friends, support each other, and **share our fears and concerns without feeling judgement.**”

NEGATIVE EFFECTS

“It creates long periods of time where **we are apart** due to hospitalizations, or travel for medical appointments. It causes **financial strain**, which leads to conflict. It causes **jealousy** when more time is spent with the ill child than the spouse. It causes **conflicts** over parenting and medical decision-making philosophies.”

“It is exhausting and your lives become more about the child than the relationship between the two of you. It can sometimes become **more like an exchange of information than a loving relationship**. Sometimes you are just too exhausted to make a 'date night'”

“My husband and I are actually **filing for divorce** - I believe the stress from our daughter's early birth and special needs drove us apart.”

“**We snap at each other** sometimes and argue when we are really stressed out. The attention our daughter needs makes us feel disconnected from each other sometimes. And **we don't get to go out** as a couple together much.”

PARENT ADVICE ON SUPPORTING YOUR OWN SPOUSE/PARTNER RELATIONSHIP

It's really important to try and walk in the other person's shoes. If something is on your mind, think through how you are going to express this to your spouse-don't attack-this is not an opportunity to take out your frustrations but to explain your position. If you think about what the real issue is and focus on that, you can have a positive exchange and come to decisions and resolutions together.

We have learned to spend time together in small ways, as well as electronically/digitally when apart. We have learned to prioritize our money and to balance medical bills with non-medical needs. We have had extensive discussion regarding how to make parenting and medical decisions, and what our true priorities are. We have prayed, and asked our friends and church to pray, for our relationship.

We try to keep in mind each other's stressors. We share responsibilities as much as possible. Most important we keep our sense of humor.

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR OWN FRIENDSHIPS?

POSITIVE EFFECTS

“Having a child with special needs helps **clarify the nature and strength of friendships.**”

“I have found **new friends with shared issues** who I would not have met otherwise.”

“I'm a better listener and **I know who to turn to** for fun and relaxation, inspiration and energy and the best shoulder to cry on without feeling like a failure.”

NEGATIVE EFFECTS

“I feel like **it's hard to talk about kids** in general. They will say something like how their kid is going to the prom or college and I feel I can't add anything. My kid will not do those things.”

“Our friends often must deal with **our having to cancel** outings or back-out of events with short notice, due to the needs of our child. We have also **imposed upon our friends** a great deal.”

“People can't relate so **they drift away**. Also, people try to sympathize but trying to make it relate to their kids and you really just want to scream that **they in no way actually get it.**”

PARENT ADVICE ON SUPPORTING YOUR OWN FRIENDSHIPS

Join support groups. They understand what you're going through.

Make the effort to keep in touch when you find yourself with free time. If you stop reaching out, so will they.

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR RELATIONSHIPS WITH EXTENDED FAMILY MEMBERS?

POSITIVE EFFECTS

“Have **had to team together** to work together for the benefit of the children.”

“It causes our extended family to realize that **spending time together is important**, and that making an effort to build relationships now, as opposed to the future, is important.”

“**Our son has been an inspiration** to our extended family.”

NEGATIVE EFFECTS

“I feel like **my family is embarrassed** of my child. **His family seems overwhelmed**, or whatever issues they have, so they seem to stay away.”

“I feel **I am often being judged**. Maybe they think I caused her autism or I am a bad person and that’s why God gave me two sick children.”

“We have received **extensive criticism** regarding how we make medical and parenting choices. We have had to **cancel multiple trips** to visit extended family, and we have been unable to fulfil extended family commitments as a result of caring for our child, and the financial strain this care causes. We have also dealt with a large amount of **denial and downplaying** of our child's actual care needs and circumstances.”

PARENT ADVICE ON SUPPORTING YOUR RELATIONSHIPS WITH EXTENDED FAMILY MEMBERS

Talk to them about all the things your child has accomplished. Let them see how much you love your child.

Unfortunately, either you have supportive, understanding family/friends or you don't. Even if you try to explain your situation, if someone really doesn't want to hear it, you'll get nowhere. It's better to look for support outside of your family and make new friends with people who get it.

We discuss the reality of the burdens a child with complicated medical needs creates, and what expectations by extended family are, and are not, realistic as a result. It is a work in progress.

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR RELATIONSHIPS AT WORK?

POSITIVE EFFECTS

"I am more patient and accepting since my son - this allows me **to get along better with others.**"

"I realized that my former profession was not compatible with life with a child with complex care needs, and **have changed careers**, and now work in the community of families dealing with complicated medical needs. **This has been a wonderful life change.**"

"My work revolves around special needs kids, so gives me **more empathy and insight** into issues faced by these families."

NEGATIVE EFFECTS

"I must work from home, in order to care for my child concomitantly; I can **work only limited hours**, I often must **miss meetings** and events that require travel, and at any moment I may need to **drop all work** efforts focus only on my child's needs. All of this makes work more difficult for my co-workers."

"People at work will plan a get together. I usually can't go or won't go because of my kid's needs. Again, **hard to fit in socially**. I feel like I don't really want to talk about my 16 year old in diapers."

"Stressful. Boss gets aggravated with amount of time off. **Can't get promotions**. Work friends get angry that you're **not doing your fair share.**"

SUPPORTING WORK RELATIONSHIPS

Do as much as you can do and try to let the rest roll off your back.

Provide training on the importance of working for special needs parents. Create a special classification (like FMLA) to protect parents in their jobs or allow them to do their jobs in a remote or geographical location without penalty.

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOU PARENTING YOUR OTHER CHILDREN?

POSITIVE EFFECTS

"I have **more patience.**"

"I would say that it has positively affected my parenting in that we spend more **time together** as a family, and have an **incredibly close bond.**"

NEGATIVE EFFECTS

"I am **tired and often lack patience** more often with him than his sibling."

"There are times when **the needs of one supersede** the needs of the others."

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR COMMUNITY INVOLVEMENT?

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR INVOLVEMENT IN YOUR CHILD'S SCHOOL COMMUNITY?

POSITIVE EFFECTS

"**Got me very involved** in my child's education, understanding curriculum, working with teachers and therapists, joined parent councils, pay attention to issues important to the schools & families."

"It's amazing how **the help we have provided in supporting school activities has greased the wheels** for getting what our child has needed in school as well as some well needed slack on her."

"**They are the extended family.**"

NEGATIVE EFFECTS

"A lot of the school community involvement happens around socializing and taking part in events planning, etc. It's **hard to make time commitments** to these, when you are never certain about your child's health."

"Sometimes **there can be friction** based on her needs and what the school thinks they can handle."

"Teachers weren't following the 504, so **I took him out of school** and am home-schooling him."

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR INVOLVEMENT IN YOUR NEIGHBORHOOD OR TOWN COMMUNITY?

POSITIVE EFFECTS

"My personal standard is to improve access - not create special access for just my child. **I've gotten involved in many local efforts.**"

"Our child needed to take twice daily walks so **neighbors began to see us all over.**"

NEGATIVE EFFECTS

"He does not engage in local town sports so **we do not travel in the same circles** as my neighbors, etc."

"Our **ability to participate** in neighborhood activities **has been limited.**"

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR INVOLVEMENT IN YOUR FAITH OR SPIRITUAL COMMUNITY?

POSITIVE EFFECTS

"As a family **we have become deeply involved** in our faith as a result of the difficulties that our family has faced. We have also **helped our church community to draw closer to God**, as they have watched, and helped, and struggled with us in our difficulties."

"Has deepened our faith and **extended our faith community** to other religions."

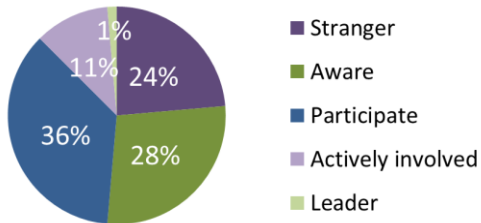
NEGATIVE EFFECTS

"We have had many, many weeks where we have **missed church**. We have had limited availability to work in church activities, and have had to **pull out of events** and activities at the last minute. We have also **needed a great deal of help** from our church to get through our struggles, financially, emotionally, and spiritually."

HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR COMMUNITY INVOLVEMENT?

More than half of parents described themselves as not participatory in their community ('stranger' or 'only aware').

How do parents describe their community involvement?
(72 parents reported.)



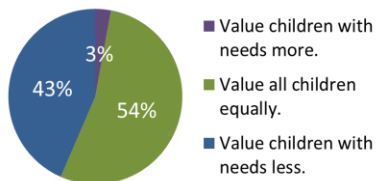
"Our city was the 1st to install vision-impaired curb-cuts everywhere; almost everywhere we go to is designed for inclusion. **We love where we live.**"

"I like and feel the need to help in my community and connect with others. I had done that since I was a child and young adult and got out of community involvement after my daughter was born. However, I began getting re-involved in community events when she became more independent."

HOW DO YOUR LOCAL COMMUNITIES RESPOND TO CHILDREN WITH MEDICAL CHALLENGES?

More than half of parents felt that their local communities valued children with medical challenges and children in general equally.

Do communities value children with medical challenges differently from children in general?
(69 parents reported.)

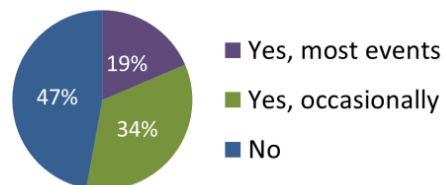


"My community **does not have enough accommodations** to make participation with my child easy and stress free."

Some parents have been offended by community members' reactions to or attitudes toward their child with medical challenges.

"Skipping is easier than leaving early/being interrupted. **They may be sympathetic to my children but not me.**"

Do parents skip social events to avoid offensive reactions?
(70 parents reported.)

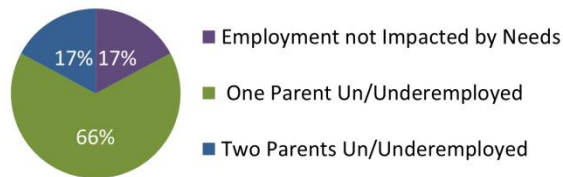


HOW DOES HAVING A CHILD WITH MEDICAL CHALLENGES AFFECT YOUR FINANCIAL SITUATION?

EMPLOYMENT

Many parents hold a paying job but most families are suffering from un/underemployment due to their child's healthcare needs. Some parents work more than they would like due to financial considerations related to their child's healthcare needs.

Are parents un/underemployed because of their child's healthcare needs?
(75 parents reported.)



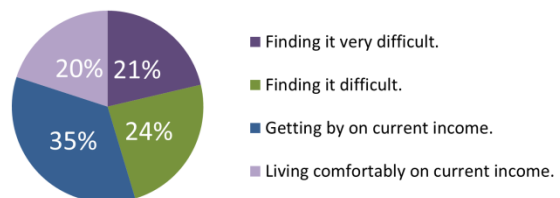
"She missed 102 days of school last year we have no nursing. **How am I supposed to keep a job?"**

FINANCIAL COMFORT

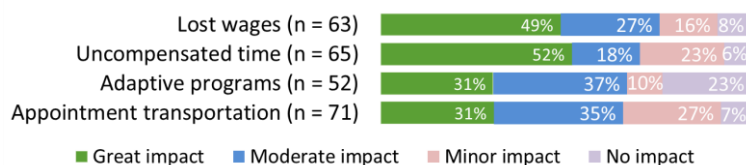
Nearly half of parents described their family's financial comfort as difficult or very difficult. The strongest impact was from lost wages, uncompensated time, adaptive programs, and appointment transportation. Parents are having difficulty affording what they need in many categories and cannot often afford what they need and want. Most parents did not use a financial planner.

Are parents financially comfortable or finding it difficult?
(75 parents reported.)

"It's tricky. We don't always see the same when it comes to **defining needs and wants.**"



What is having the biggest impact on parents' finances?

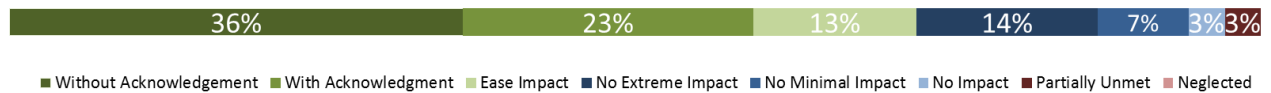


"It has created **even less time for us as a family** because we have to spend all our free time trying to earn extra money."

CAN PARENTS BALANCE FAMILY NEEDS WITH THE NEEDS OF THE CHILD WITH MEDICAL COMPLEXITY?

Most parents reported only considering the child's needs, either with or without acknowledgement of the impact on siblings or parents, or with some efforts to ease the impact on siblings and parents.

How do parents prioritize the needs of their child with medical complexity and the needs of the rest of the family?
(69 parents reported.)



MEETING ALL NEEDS WITH NO ACKNOWLEDGMENT OF IMPACT

“Any appointment we have is based only on what the child needs. In fact, many times, **I have to argue quality of life and bring the whole family into it** and make physicians realize that not everything is realistic.”

“Other than a few rare instances, the focus is on the child being discussed, and how their care impacts others in the family does not appear to be considered. Most of the time we can make it work, but **there have been times when one child's care has impacted the rest of the family so much that we needed to seek other options.** This has not generally been received as well I would have hoped.”

MEETING ESSENTIAL NEEDS; OPTIONAL CARE IF ONLY MINIMAL IMPACT

“Optional care is discussed but recommendations are made **depending on financial impact** on our family.”

“I have so many doctors and things that I need to track. The most recent doctor acknowledged that I have a LOT to do so **do my best.**”

WHAT PARENTS WANT THEIR CHILD'S DOCTORS AND MEDICAL SPECIALISTS TO KNOW

- Complex care is...complicated, and not something any parent is trained to handle. Instead of seeing us as difficult, consider the possibility that we are struggling and don't have the ability to deal with this any other way. Consider that we are all doing the best we can with what we have to work with. Please give us an example to follow instead of constantly challenging us.
- Help us to advocate for transitional support in the medical community as your patients (our children) enter young adulthood. Schools do little to map out a sound transition plan they focus solely on the academic needs of a child and are not equip to handle children with complex medical needs.
- Coordinate appointments to minimize frequent visits and respect our time. Doctors need to work in real teams and need to communicate with other to optimize the child's health. PCPs should be more involved in coordinating care. Don't automatically refer us out or leave it up to parent to figure it out where to go next.
- I always appreciate when doctors talk to my son directly and not just me. It helps the both us know that the doctors appreciate our child and his opinion. He has a voice in managing his care.
- Our goal is quality of life, and avoiding the ER at all costs. If you can help us do that, you've healed my soul.
- Parents decisions on intervention should be respected when options are presented or medical opinions differ. Having a complex child does not relinquish parent rights to the opinion of medical personnel.
- Realize that most of these children are doing their best to exercise and get better. It's horribly difficult to function with chronic illness and these kids need compassion.
- Specialists—do some checking around before you say you cannot help. You need to be open to working with other doctors so that things don't get missed especially when you are dealing with a child that has more than one condition. You need to work together for the benefit of the patient—consider alternate options. Don't send the patient from place to place leaving the parent to identify problems or to navigate the system on their own.
- Your patients are whole humans—not just a single system, despite what you prefer to focus on. What you do in one area affects the whole person. Too often, parents are forced to take on the roles of a provider because so many providers do not follow through. Parents should not have to decipher problems like complex medication interactions. Think before you prescribe.
- Primary care — stop looking at me like I have five heads. If you don't know enough about the condition, write the referral. Don't let that kid continue to suffer and go undiagnosed because you are afraid of looking stupid.

Thank you for taking the time to share your experiences through these surveys and to read about the experience of other Franciscan Helps Families Connect parents through this report.

If you know other parents who would like to join, please send them the link below.

Parents can join the project at any time – you don't have to complete all of the surveys to participate!

www.franciscanhospital.org/FHFC