

FRANCISCAN HELPS FAMILIES CONNECT

PCORI PARENT ENGAGEMENT PROJECT

SUMMARY OF RESULTS OF SURVEY 2

This report contains a summary of the responses parents provided in Survey #2. We are grateful to the **126 parents** who completed our second survey and shared very important information about caring for their children with complex healthcare needs. 61% of the survey participants were from throughout Massachusetts representing different healthcare systems; the remaining 39% were from other U.S. states.

Survey #3 will be emailed to you in early August. This survey will build on issues parents identified in Surveys #1 and #2 as well as new topics requested by the parent participants, including the impact of summer vacation on your child and their services.

We cannot thank you enough for your responses. Please be sure to complete Survey # 3 – each survey contains different but equally important questions!

Parents can join the project at any time – you don't have to complete all of the surveys to participate! Please share the link below with any parents that you think might be interested in joining our project!

www.franciscanhospital.org/FHFC

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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.

I. SURVEY HIGHLIGHTS

Parents provided us with 67 pages of information in Survey #2! We have tabulated and summarized the parent responses for you in this report. Here are some key highlights from Survey #2.

- Nearly all parents reported **good communication** with their child's primary care doctor.
- Nearly all parents reported **good communication** with their child's medical specialists, although parents felt that the *specialists relied too much on parents to facilitate communication among doctors.*
- Most parents had concerns about **communication among** their child's doctor, specifically with *conveying information between doctors.*
- Most parents had **disagreed** with their child's medical specialists' recommendations, especially when *the specialist ordered tests or procedures the parent didn't think were necessary.*
- Very few parents felt they could **not openly disagree** with their child's primary care doctor.
- Some parents felt that they could **not openly disagree** with all of their child's medical specialists without the *specialist feeling that their authority was being challenged.*
- Some parents had been concerned about **being labelled a "problem parent"**, even *when sharing valid concerns.*
- Nearly all parents were **satisfied with the medical care** that their child received.
- Some parents reported needing **more help coordinating** their child's care, especially with *coordinating multiple specialist appointments on the same day.*
- Most parents encountered problems **getting an accurate diagnosis**; they found it difficult *getting healthcare providers to listen and believe their concerns prior to having a diagnosis.*
- Some parents felt that their child's **treatment plan was not ideal.**
- Some parents felt their child did not receive the **necessary medical care** for their needs.
- Nearly all parents felt their child's **medical team cared enough** about their family's values and goals of care.
- Some parents did not feel confident that they could rely on their child's care providers to **accurately assess** their child's medical issues.
- Some parents felt that the referrals their doctors gave their child to see **other providers were unnecessary.**
- Most parents felt they must **assume the responsibilities of medical professionals** to research issues related to their child's care or medical condition.
- Some parents had **accepted a treatment plan** that they didn't think was best for their child.

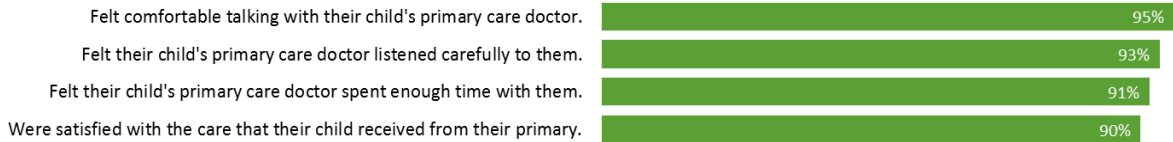
Thank you for your responses!

We look forward to hearing your voice in Survey #3 when we address many new topics!

II. TABULATED SURVEY RESULTS

COMMUNICATING WITH YOUR CHILD'S PRIMARY CARE DOCTOR

Most parents:



REPRESENTATIVE DESCRIPTIONS OF UNMET NEEDS

- I feel like our PCP spends enough time with us but I feel like it is just me catching her up about everything going on with all of the other doctors.
- My child's doctor is very unsure of what to do for my daughter and always defers to specialists.
- My son's PCP tends to be a 'wait and see' kind of doctor and I often need to request bloodwork and/or testing, since he is not as proactive about it as I would like.
- Overall we are pleased. However, if he would take more initiative regarding my child's care and plan it would help. I'm always the one proactively reaching out to ask for things. I never get a call that says 'hey based on this test we think the next step is XYX.' I'm always leading the charge myself.
- Our PCP is doing a great job, but in the end she's not a complex care doctor. She can do the wellness stuff, or the regular illness stuff. But not help us sort out the big picture 'which specialist would we even talk to, we don't know what's wrong.'
- Our PCP needs to work on preparing my child for taking own responsibility wherever appropriate. Seeing her alone (without caregiver), discussing specialist results with my child and helping to transfer care to an adult primary care doctor
- We are part of a complex care clinic which SHOULD be the 'quarterback or coordinator' of all the specialists. HOWEVER, our primary care doctor refers us back to each individual specialist for each problem even when the issues overlap. The primary care doctor also requires us as parents to do the conversations between physicians when concerns arise. This leads to an appearance of coordinated care but is very disjointed.

COMMUNICATING WITH YOUR CHILD'S MEDICAL SPECIALISTS

Most parents:

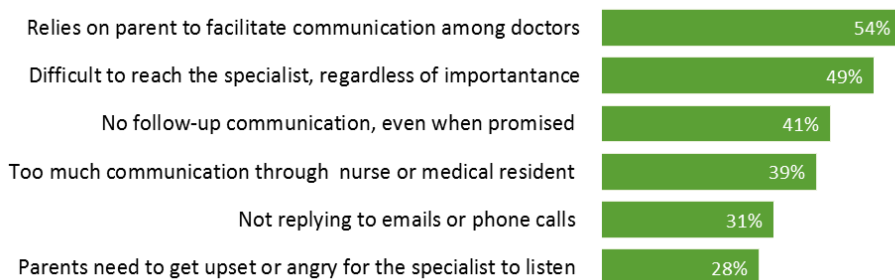


REPRESENTATIVE DESCRIPTIONS OF UNMET NEEDS

- A willingness to have conversations about my son's TOTAL care, including our use of 'tools' outside of their toolbox. Things that are not related to surgery and medications. We tend to have very one-dimensional conversations.

- All of our son's medical specialists are very good at what they do; we just wish they would communicate better with each other and look at the overall health of our child when making decisions
- My son sees about 9 specialists. GI and Allergy and Immunology have great collaboration with each other. The other disciplines rarely talk to one another. I get pretty tired having to be the glue that holds everyone together.
- For some reason they disregard his mitochondrial diagnosis or feel it is irrelevant.
- I do not like being left to fend for myself when it comes to my son's trach problems. .
- I feel rushed through the appointments, often times I don't get to ask questions or comment. Decisions are made on the fly without time to research.
- I wish they were more efficient. I feel like I make a lot of unnecessary follow up appointments and spend a lot of time waiting in between doctors. I wish they could almost come together so they don't have to waste my time asking me the same questions and making my son repeat the same tasks like 'can you walk on your heels' a million times.
- I wish they'd communicate better with each other to develop a comprehensive care plan. We often receive conflicting opinions and treatments from each specialist.
- In my opinion, I should consult with the doctor about my son's issues at least once a week, not once a month.
- My son is sick a LOT and yet we are able to manage his care primarily at home. If he was hospitalized more often, I think specialists might be more proactive in considering ways to promote health and prevent hospitalizations. I wish they understood the quality of life impact on frequently being home from school sick.
- In general, Specialists do not listen or spend enough time with you. They don't want to 'investigate' your problem or explore the possibility that there may be another solution, but simply check off their box and move on. They don't realize that in our world a 3 or 6 month follow up to 'check again' is an eternity, especially when your child is having a recurring problem.

31% HAD CONCERNS ABOUT COMMUNICATING WITH THEIR CHILD'S MEDICAL SPECIALISTS



REPRESENTATIVE THOUGHTS ON THE TOPIC

- As a parent, I may not be able to put my concerns in “DoctorSpeak” language.
- Communication from admin to nurse to doctor is not relayed correctly.
- I don't always feel comfortable that my child's specialist will keep my child's health information as private as I would like it to be. I do not want everyone else in the hospital where our specialists work discussing the care choices my family and specialists make for my child, but sometimes other providers who are not on my child's care team insert themselves into our care and argue with our specialists about the care choices made.

REPRESENTATIVE DESCRIPTIONS OF HOW THESE ISSUES AFFECTED CHILDREN OR FAMILIES

- It has been difficult to get everyone on the same page, also with physicians making comments about how they can't do 'their job' because another specialist is requiring a certain treatment and that affects how my child's quality of life. Also physicians have said they would 'check in with other physicians' and then no communication happens back to us as parents to know if the communication has actually happened or what the decision was. This results in continued poor communication.
- Our family is experiencing a lot of stress as a result of the constant need for us to be 100% on top of our daughter's needs instead of it being spearheaded by a medical professional.
- Parent constantly has to be on alert either to make yet another phone call or to make sure the specialist is aware of everything going on with your child. This leaves parents feeling the weight on their shoulders instead of the medical profession.
- Scary to push for what you think is right, especially when symptoms are hidden or vary. Worried that I may sound disagreeable, especially when stating that things that work for others are not helping my child.
- The few specialists that I can communicate with directly (text, personal email) I have the best relationships with. They seem to listen to me the best, really understand my daughter the best, and they don't miss out on the things the nurse might filter because she didn't think that bit was important. They have a more complete picture.
- The specialist gets a very limited snapshot of my child, based on what they see that day. I have to remember all of the details from the different providers and with limited clinic visits/time every doctor gets the very short version since he has lots of providers to give updates on. Little time is left for conversation around today's care and looking ahead.
- They have almost overdosed our son by not communicating with one another. I am worried as a parent what if I mess up and forget to pass something important to the other specialists. It is frustrating because they all work at the same facility.

REPRESENTATIVE SUGGESTIONS FOR IMPROVEMENT

- A one-stop appointment coordinator.
- A way to communicate with the doctor directly. The hospital that we use has an online system where you can message doctors; however, many doctors have their nurse checking that. I am very grateful anytime I get a response from a doctor online, or even the nurse if it answers my question but all too often we are given the generic response to something without thought for our child, causing a delay in care.
- Provide a medical conference with all of the child's specialists arranged by pediatrician. Be willing to communicate directly with parents. If you are getting info via a third party, such as a nurse, you are not getting all the info.
- Electronic medical records have improved things somewhat - docs just need to regularly case conference on complicated kids - in person or via media tools.
- Hospitals need to make more serious efforts to restrict private health information from non-treating doctors within a care system. My child's records should not be open to any doctor within a hospital or care network; there should be a level of professional involvement with my child's care before access is granted.
- I do basic things like when I do get in to see his neurologist I have my questions ready. However if I think of something later (leave a message or send an email about it) it usually never gets responded to. I hate to call the Ombudsman but I am heading in that direction.
- If my child sees a doctor 1x/year or more, then they should be receiving the clinic reports from ALL of the other providers. Doctors need to make time before our clinic visit to review all of these reports so we can start the conversation from there and not spend so much time reviewing the past.

- Including parents on emails and all decisions to be a transparent cohesive team would increase a LOT of trust between parents and providers.
- I would love for ANY of our physicians to SINCERELY ask what we want for our child, what we hold important and value. Then re-direct our care goals as best we can to that.
- I don't know anything about medical stuff but I know my son and all I ask is to be considered a vital member of the team.
- Having e-mail or phone systems flag whether a message has been responded to - highlight to specialist which messages may have been overlooked?
- One site where all doctors and specialists can access all data and parents can ask questions.
- Specialists need to communicate with parent and others working more consistently with child - what about sending a 1-page questionnaire to PT, OT, SLP, teachers to get a more comprehensive picture of child before a scheduled appointment. I will often ask specialists working with my child for anything they think is significant to discuss at an appointment but I have to be the keeper of all this information. Would be super if someone were there to help facilitate that transfer of knowledge.

COMMUNICATION AMONG YOUR CHILD'S DOCTORS

57% HAD CONCERNS ABOUT COMMUNICATION AMONG THEIR CHILD'S DOCTORS



REPRESENTATIVE DESCRIPTIONS OF HOW THESE ISSUES AFFECTED CHILDREN OR FAMILIES

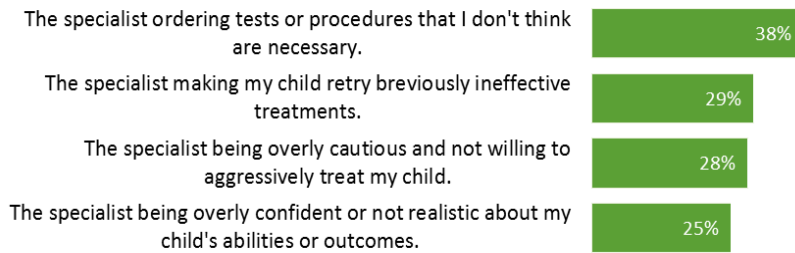
- A lot of pressure on parent to try to gather every scrap of information in any appointment, attempting to anticipate what other specialists will want to know.
- Although we have specialists in different locations, I make sure that they all have the same information. It would be nice if they read it before seeing her and asking questions they could have read on the report.
- Confusion increases our workload - more phone calls, emails trips to pharmacies, clinics, etc., and also miscommunication can lead to medical errors.
- Doctors aren't seeing my daughter for her whole body, and sometimes suggest solutions in conflict with other doctor recommendations. Some of which would have been horribly dangerous for us.
- Extra and unnecessary time, travel, money and medical tests were required. In the long run he was incorrectly diagnosed and other medical professionals would not listen to my concerns regarding the diagnosis or my request for the test to be done again.
- You feel overwhelmed because you're not sure who's right and who's wrong. Which doctor do you listen to, the one with specialized training or the one who knows your child the best?

- I like the doctors knowing what is going on and whether they approve of the change. Since they do not respond anyway how can I tell the difference between them just not responding again and knowing but not having any concerns?
- It has meant extended hospital stays when, if proper communication had been in place, my son could have been home sooner.
- It is stressful as a parent having to have the knowledge to report accurately to each specialist... Something I may find benign could actually be very important ... I am her parent and that is what I want and need to be... If I wanted to go to medical school I would have gone!
- Every med change, I need to call 13 other specialists to inform them, and ask if they agree, or if it will affect something they are doing. It is very time consuming and puts lots of stress on me as single parent.
- Right now I have several doctors upset that one doctor is taking so long to do some things, however they are just telling me they are upset, which does not do anything because me telling that doctor that other doctors are mad does not have nearly as much weight as doctors talking to each other.
- My son is sick a lot. In my lay opinion it is a combination of his heart/lung function, nutrition, low muscle tone, among other diagnoses. I often wonder if we looked at all the systems, we might be able to brainstorm a whole body approach to wellness.
- Too much time elapses trying to coordinate communication among these specialists ... but if I don't keep working at it when I can it would never happen at all.
- While we have a central point person, we lack a care plan leader, which means oftentimes treatments and procedures are delayed because no one wants to be the person to approve something or take a risk. They defer to other specialists and we go in circles when there are conflicts.

REPRESENTATIVE SUGGESTIONS FOR IMPROVEMENT

- Collaborate! At times, it seems like doctors are mistaking HIPAA for proprietary rights to her medical information. It is *supposed* to be shared between her medical caregivers!!
- Having a primary doctor , not the PCP, responsible for coordinating all the specialists
- I see PCP and all specialists at one place that has online electronic medical records.
- I would love to have a bi-annual check in with all specialists to redefine goals and treatment plans in a cooperative manner. Either in person, via email, skype, etc. Looking at the case with fresh eyes and not reading notes that are outdated and/or incorrect.
- If you know a child is seeing other doctors, doctors should invest time in learning who they are, asking for reports to be sent to you. Just be aware of what else is on the table for the child and family.
- Input notes into electronic chart and send messages; don't rely on parent to convey disagreement.
- Our hospital just started a Complex Care program. They coordinate appointments, serve as a go between with multiple specialists and help with planning care. It has changed my world! It has freed up many hours of my time, greatly reduced my stress and best of all improved my son's care.
- Some way to keep all test results in one place for all doctors to see.
- Speaking in person as a team... No phone calls or emails. With the chart in front of all of them!
- Specialists' reports should highlight important points for PCP.
- The doctors should review her chart before coming in to talk to us.
- They work in the same hospital for goodness sakes, they are on the same portal of info, there is really no excuse for this.
- In the past, all consults ended with the doc writing a formal letter with his/her impressions and ended with 'Thank you for the opportunity to consult.' Where did that courtesy and teamwork disappear to?
- When important decisions need to be made, a group care meeting can be very helpful for a family to see that all providers are on the same page to help put family at ease. We have done this inpatient but could be even more useful when managing complex cases outpatient. Disagreeing with Doctors

63% OF PARENTS HAD DISAGREED WITH THEIR CHILD'S MEDICAL SPECIALISTS' RECOMMENDATIONS



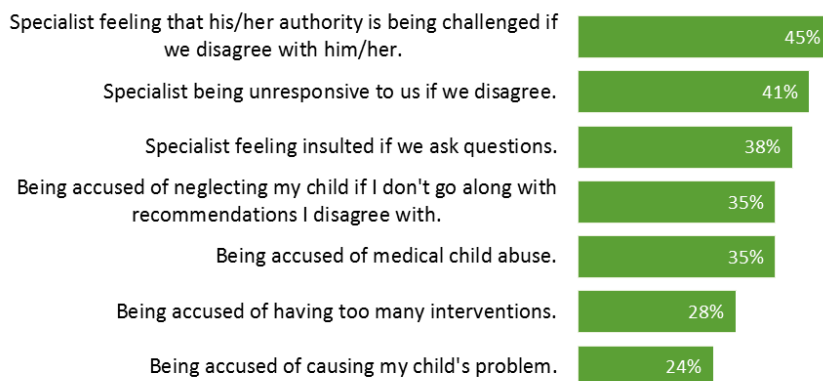
REPRESENTATIVE THOUGHTS ON THE TOPIC

- I'm more cautious about introducing new medications and more concerned about potential side effects than most of my child's doctors.
- It has only happened twice. First time was a medication that I felt wasn't a good fit for my daughter. The second time was asking for a diagnosis that I had researched; the doctor dismissed me saying my daughter didn't have the 'classic symptoms'. Two years later, a new neurologist did give my daughter the diagnosis that I felt she had.
- Sometimes mental health and well-being trumps the treatment choices.
- They have recommended aggressive treatments (trache) when we wanted to less aggressive treatments (CPAP) first. 8 years later, we are still thriving on CPAP - not TRACHE -- and have saved tons of money.
- It is the squeaky wheel that gets the grease.
- Too many want to take a 'wait and see' approach while my child falls further and further behind developmentally.

OPEN DISAGREEMENT

8% felt they could not openly disagree with their child's primary care doctor.

23% felt that they could not openly disagree with all of their child's medical specialists.



REPRESENTATIVE DESCRIPTIONS OF HOW THESE ISSUES AFFECTED CHILDREN OR FAMILIES

- I feel I should be able to disagree with a doctor (in a nice way, or respectful way) without worrying about that doctor's ego. A doctor has the medical knowledge and I respect that, but I'm the one who lives with my child 24 hours a day and know more than you think about what my child feels or needs.
- I have had to develop strategic skills for how to navigate the different personalities of the doctors, how to avoid conflict, how to 'decompress' after clinic visits, how to prepare my child before certain doctors and after always affirm our beliefs and approaches to his care. One example is I never bring my calendar with me, so I cannot be pressured to make an appointment for a certain procedure.
- My child is suffering longer because I wait longer to contact them when there is a problem.
- We have agreed to care plans we feel are not in our child's best interests simply because we judge the risk of causing trouble by disagreeing is greater than the risk of agreeing to poor or inappropriate care plans.
- Some doctors get very upset when I come with a list of questions. Additionally, they sometimes get very hostile when we start asking the questions about their thought process of what led them down the road for their thinking.
- Sometimes just going along with unnecessary treatments that have no positive effect so I don't look like I'm arguing with a specialist..

REPRESENTATIVE SUGGESTIONS FOR IMPROVEMENT

- Always keep the partnership in mind. I have to have this person involved to keep my child well - they know this particular area better than I do and they have the credentials to prescribe the medications, therapies, or services that [my son] needs.
- I disagreed with my child's doctors when they wanted to do three invasive surgeries to my son. I went home, did some research at home and found a homeopathic remedy to my son's problem. No surgery, problem fixed.
- I play down my research & accumulated knowledge and ask lots of questions. If I'm really confused, I say so and ask for clarification, time or referral.
- I keep a detailed logs of symptoms etc., to show that I'm not making things up. Also involve my sons therapists and school nursing staff in reporting so there are others to report on what they've seen.
- I usually try to phrase things using terms such as 'My understanding i..', 'It's been my observation...'', etc.
- One strategy we have is for me to go to clinic alone and not together as parents. This way I can always say 'I need to discuss this with my husband first.' This allows me to respectfully receive the information the doctor is providing and their recommendations, while also deflecting the pressure to make a decision on the spot --even when I already know that we won't be going with the doctor's ideas. I then can follow up by phone with the nurse. This is very effective when you have a doctor with a strong personality.
- Slow them down. They have a tendency to rush into conversation and what they want to do. When all else fails, call patient relations.

37% HAD BEEN CONCERNED ABOUT BEING LABELLED A “PROBLEM PARENT”



REPRESENTATIVE DESCRIPTIONS OF HOW THESE ISSUES AFFECTED CHILDREN OR FAMILIES

- As a single parent of a child with autism, among a host of other issues, I am the only one that can accurately report what I see for my son. Often brushed off because ' he looks good' or ' his weight is good' or ' he looks happy...' I feel like they think I am manufacturing issues.
- I am careful about how much I call a doctor office because I don't want to be labeled as a problem parent. Sometimes this means we have to wait longer for results for tests because they forget to call back.
- I want to have a good relationship with my child's doctors and I want to be a part of the team but it worries me to be seen as a pain instead of a help so I only bring things up when I feel like I have to.
- I feel sometimes that they want me to make decisions when I am looking for input from those who would know how to better treat him
- I have learned to video or photograph everything. Seeing is believing.
- I sometimes feel as if the doctors think I believe my child is healthier than he is and don't understand his true situation because I make decisions with the mindset that he will get better and be 'normal' someday. I do understand, but I'm selling my child short if I do not try to make his life as normal as possible.
- My son is over 18. Although I am his caretaker my son is very articulate and it is assumed by the specialist that what he says is the way it is. My son has Asperger's so his reality can be very different than mine. I have a much better idea of my son's medical care but come off as the controlling mother.
- Sometimes I'm caught between the specialists and my husband. I'll tell him what they said at home after we've come back from an appt. and he disagrees and wants me to tell them this, that and the other thing. It's complicated.
- The concerns we have about communicating with my child's specialists have resulted in our being less than forthcoming regarding my child's medical problems. We have to carefully decide which of my child's medical problems we should discuss, and which we should leave out, based on our prediction of how our medical specialists will respond to each problem.
- When dealing with rare diseases I often know more about my son's syndromes than nurses and even doctors in the ER and even in our clinics when he was first diagnosed. When going to the ER, sometimes I am lucky enough to come across a seasoned doctor who sees me as a help and wants to utilize my knowledge, but I never know what I face so I am sure to call all of my regular physicians when entering the ER for back up. It is a scary place to be as a parent trying to care and prevent

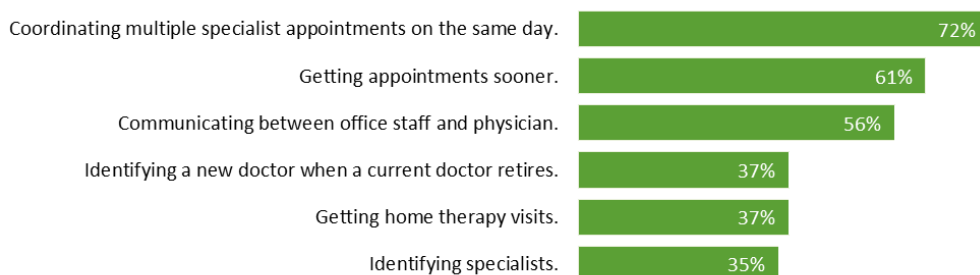
anything from happening to your child and fearing that that advocacy could cause separation between you and your child.

REPRESENTATIVE SUGGESTIONS FOR IMPROVEMENT

- Do not get upset or overly emotional, raise your voice, or argue aggressively. Clarify that you understand the doctor has the expertise to make diagnoses and to offer care choices, not the parent. The parent's job is to choose between care options offered by the specialist, based on what the parent thinks is in the child's and families best interests
- Have more training for doctors to have them try to understand the psycho-social issues surrounding caring for a medically fragile child. I feel so often that doctors try to insulate themselves from dealing with the everyday reality of a child who is sick that they often times blame parents for the biomedical solutions not working, when really not all treatments work on ALL patients.
- I did get my son to give his PCP permission to communicate with me via online electronic site the medical center has set up where I can ask questions and express my concerns.
- I often will only let them poke [my son] twice. If they still fail to get a vein they need an IV specialist or a vein finder. This gives me a bad name with nurses but is best practice for my child.
- I think it's up to the parent to educate themselves on their child's condition and to not feel intimidated by medical personnel.
- Keep good records and take lots of pictures so they can see what I am seeing.
- Listen at least as much as you ask questions or talk. And do your research.
- Sometimes you just have to accept the label and push for what your kid needs.
- Show appreciation first before going into your concerns. Make an effort to show the balance what is and is not working. That way, professionals you are working with will see that you are not a problem but are a parent who is carefully thinking matters through.
- Smile, ask questions instead of demanding resolutions, and be friendly even when you're exhausted.
- Specialist (and support staff) should be sure to be affirming as much as possible, and validate concerns even when (to them) it seems trivial. If it was trivial to me, I wouldn't be calling!!
- This can happen after inpatient stays. I'm tired my child is tired. Presenting yourself in sweatpants after days in hospital is hard. Especially with new overly confident docs!
- We have always said - relentless respectfulness when communicating - and breathe!

COORDINATING CARE

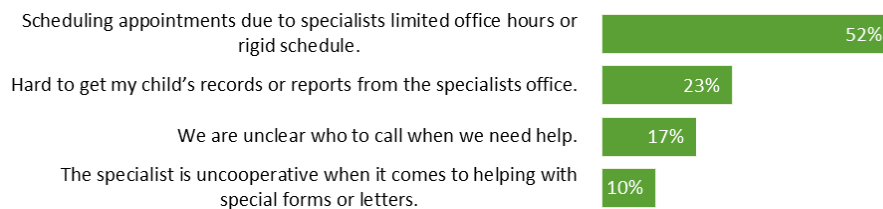
43% REPORTED NEEDING MORE HELP COORDINATING THEIR CHILD'S CARE



REPRESENTATIVE THOUGHTS ON THE TOPIC

- Need to find ways for there to be a team approach to care and foster open dialogue between all members of my child's team. It is difficult being the parent, advocate, and keeper of all the knowledge. It would be nice to have some assistance and yet I would always want to be the one leading the team for my child's care.
- Helping to get an appointment so I don't have to wait months when she needs to be seen and coordinating her appointments so I don't have to make numerous trips to the city in the same week.
- I finally found a doctor whose job it is to coordinate with the different departments; I just wish the communication was more frequent.
- It would be helpful to have someone else besides myself analyzing my son's medical situation and determining what specialists to consult and what testing/treatments to pursue. My son's conditions seem to be too complex for his PCP to handle adequately. I'm hoping the new complex care service we were referred to will help with this issue.

CONCERNS REGARDING COORDINATING CARE



REPRESENTATIVE DESCRIPTIONS OF HOW THESE ISSUES AFFECTED CHILDREN OR FAMILIES

- A lot of missed work time for appointments that often seem unnecessary. With travel time, my time off from work can be 2+ hours and I see the physician for 5 minutes.
- Can't correct information that may be incorrect in dictations. Would like to see results to become more knowledgeable about child's care.
- Getting copies of their reports is not easy. All the hospitals now have patient portals on line and I find those confusing.
- Have had to switch my son's Gi 3x in the past 2 years since they stopped booking appts on Fridays, which is when I can take a day off from work.
- Having to make multiple trips a month for different specialists who are all in the same hospital costing us time and money for gas and parking each time we have appointments.
- I end up pulling him out of school a lot and most of the time I have limited child care so I end up bringing my other children which makes it very distracting for all around including my son, the patient.
- I just received a phone call today that my child's doctor will now be gone the day of an appointment where she was to have a CT scan first and then we were going directly to see the doctor to talk about what was found. We also coordinated with another department to have a different CT scan done at the same time. It took work to get everything scheduled and now the doctor is going on vacation and there are no more openings to make it work to do a CT scan and appointment in the same day because it is too close to the appointment. I get that doctors need vacations, it is just really frustrating when I put all of the work in to coordinate everything for a couple of months later to get a phone call to be told it would not work. Also, many of my child's doctors only see patients one to two days a week because they are a teaching hospital and teaching. This means that sometimes we

need to make the hour drive to the hospital multiple times to see different doctors who work different days.

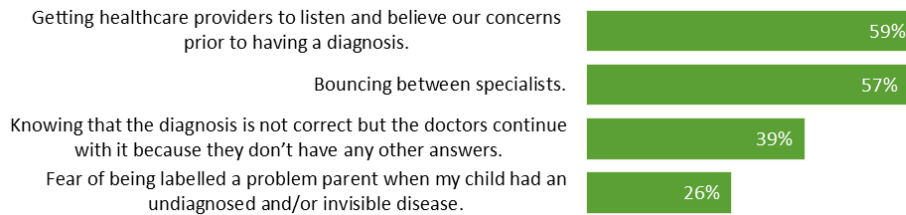
- I love my daughter's doctors. Several are tops in their respective fields. However, with the top I have found long waits for appointments.
- It's not ideal. While I could use the help from someone helping me coordinate I'm not sure I'd be able to give that up to someone else.
- My daughter does not want to see the resident then the fellow then the attending for 5 minutes. I understand they need to learn but the attending should be present for the whole visit. He bills his whole fee though.
- My son misses a lot of school and I miss work. And when we have to miss an appt due to my son being sick...we have to wait months to reschedule and generally are forced to take 1st available
- Primary care doesn't know where to send us. Sometimes they don't even know what resources exist within their own network.
- Stressful. Have missed pick up time for my other kids numerous times.
- The primary care physicians wants us to call specialists for all problems, then specialists want us to see primary care physicians who in turn sends us back to specialists.

REPRESENTATIVE SUGGESTIONS FOR IMPROVEMENT

- Collaborate! At times, it seems like doctors are mistaking HIPAA for proprietary rights to her medical information. It is *supposed* to be shared between her medical caregivers!!
- Email the PCP the reports!
- Explicitly teach and train parents to navigate the care coordination process!
- First, we need a care coordinator. Second, we need this person to be willing to support my child's needs outside of one system/organization.
- Group care clinic where the PCP and a number of specialists come to one clinic session where your child sees everyone.
- I would love to see medical case management similar to behavioral health case management. I could have one person who is in communication with everyone and who reports back to me. I have no idea how it would ever get funded...
- Keep the same schedule!
- Like to have one central point that would coordinate all clinical notes, labs, etc through and send to all involved, so all are aware of what each is doing.
- My son's syndrome does not have a 'clinic day.' I'm envious of families I know that can go for a day and see 3 or more specialists that know about child's particular diagnosis.
- Our new Complex Care program is amazing, wonderful, beyond helpful! Having this program has changed our lives.
- Receive mailed copies of the visit, and follow up notes after each appointment.

DIAGNOSIS

61% ENCOUNTERED PROBLEMS GETTING AN ACCURATE DIAGNOSIS



REPRESENTATIVE THOUGHTS ON THE TOPIC

- Fear that the diagnosis to which my child's symptoms were pointing was too controversial for the specialists to want to pursue it. Fear that we simply do not have the medical science to accurately explain all of my child's medical problems, and that this makes some providers prejudiced against my child's symptoms and care needs.
- My child is still not diagnosed and at this point I don't think the doctors are even trying to figure it out. She is stable and doing well so they are just treating what is going on.
- Our pediatrician refused to believe that our son was having seizures; she said he was just getting startled. After 5 months of her dismissing our concerns, we went to the ER at Children's Hospital Boston and were immediately admitted and stayed for 5 days until they found out what was wrong.

REPRESENTATIVE DESCRIPTIONS OF HOW THESE ISSUES AFFECTED CHILDREN OR FAMILIES

- Delayed critical lifesaving medical treatment because 'I was just a new mom and didn't know what I was talking about.' Was told my baby was just colicky for weeks.
- My child is almost 2 1/2 and obviously there is something medically wrong however we still do not have a diagnosis. For the first year and a half all we heard was 'maybe she will grow out of all of it' even though she was getting worse. It took until she was almost 2 until some of her doctors figured out that there had to be a bigger picture.
- My daughter is frustrated that they cannot tell her why this happened. She is afraid that something else might happen.
- My son's initial diagnosis was partially incorrect, leading me to believe his life expectancy was much lower than it is. Thankfully I jumped into researching his brain malformations, tracked down a team doing research and sent them his MRI. Our local clinic refused to remove the incorrect portion of the diagnosis from his records, though, and I think the perception that he had it negatively affected the care that he received from his first neurologist.
- Not knowing what the problem is, many clinical diagnoses, not knowing if there is something that affects rest of family.
- Our child is complicated and one specialist will say his condition belongs to another specialty and vice versa. Not listening to the parents has forced the child to undergo unnecessary testing or not being treated at all. This happens more with ER medical personnel who do not know them, as opposed to his specialists.
- The incorrect diagnosis caused more damage to his mental faculties that might have been prevented.
- We had concerns since birth & they were brushed aside. Saw multiple specialists each referred us back to other specialist. Finally at 10 months of age a brain MRI showed lesions indicating a terminal

neuro/metabolic disease with no available treatments. At the time my wife was two months pregnant with our second child. After diagnosis were found another pediatrician & hospital.

- We had to email the head of kidney department to finally get an accurate diagnosis for my daughter's high blood potassium. We had bounced between Fellows and stayed in the hospital for almost 40 days. Finally, I got a specialist who understood pseudohypoaldosteronism type II and started treating it. But it could have cost me my daughter's life. I diagnosed her myself by aggregating all of her medical records and determining the trend.
- We know that there are specialists who will not accept my child's diagnoses. We have to be very careful as to which specialists we see, and which hospitals we seek care at, in order to avoid pointless and harmful controversy, or accusations of overmedicalization. We have worked with our specialists to simplify my child's care, and to word his diagnoses in ways that are non-controversial.

REPRESENTATIVE SUGGESTIONS FOR IMPROVEMENT

- Trust the parents as we do our own research and may have some information to share!
- Be prepared for the appointments, know what the process is in getting copies of clinic notes, know what the process is for asking questions before you leave the office, get a name.
- Doctors should realize that parents know their child better than anyone else and that they know there is something wrong. Doctors should take parents' concerns more seriously and value the parents' input about the problem.
- For God sakes, if something is rare, do some research on your own. Contact a specialist in that diagnosis and get more information if you can. Don't balk if parents want a second opinion. Remove your ego from the equation. Saying I don't know is a strength, not a weakness.
- Get several doctors together in 1 room, have them think with the family about what could be going on. Get all of the data visible in 1 place, hard to figure out how to fix a car if the parts of the car are sitting in 4 different garages.
- I am not a medical professional....when my child is so sick and in the hospital...I have to trust the doctors to do the right thing...hopefully they do for most part.
- I think it depends on your goal. Some parents need/want a diagnosis to develop the proper treatment plan or for insurance purposes. For others, having a name for it doesn't change the situation. Both require research on the part of the parent and then being able to communicate your child's symptoms effectively.
- I wish the genome sequencing was easier and that more people were sent to genetic specialists.
- If the doctor doesn't know what it is don't automatically say it is in their head. In our mito group all the teenagers were told it was in their head.
- Insurance is starting to question why they should pay for really expensive things for a child who is undiagnosed. It is also hard when taking her to urgent care or the ER when they ask about her overall condition to give them a long list of symptoms because many different acute illnesses have different treatments depending on the overarching diagnosis. She also has a doctor waiting for a diagnosis to make the decision about a large surgery because for several conditions this surgery is contraindicated because of long run complications and we need to wait until we know what the overall diagnosis is before we can move forward with treatment.
- Physicians must be more educated and aware of rare diseases and disorders so that the time to diagnosis is reduced.

TREATMENT PLAN

19% FELT THAT THEIR CHILD'S TREATMENT PLAN WAS NOT IDEAL

- Most services are provided by school and school and physicians do not communicate outside of the summaries or reports I convey. Not certain how to fix this without compromising confidentiality.
- I don't know that she has a treatment plan, really. I feel like we are just bouncing from crisis to crisis without any overall picture or long term thought. Her primary diagnosis is CP, so to the doctors there's not some illness to treat or fix. I've had to learn about the overarching issues she's facing or could be experiencing through the internet or via the book *Caring for Children who have Severe Neurological Impairment*.
- It is super vague and is often unread or changed without our consent.
- Symptoms are still present or recurrent despite treatment. Lack of set achievable goals
- We are lacking a full treatment plan that allows him to be a kid and participate in life to the fullest. Everyone is afraid of risks of certain procedures and therefore he suffers.

NECESSARY MEDICAL CARE

14% FELT THEIR CHILD DID NOT RECEIVE THE NECESSARY MEDICAL CARE FOR THEIR NEEDS

- I think there should be something in place for him to see his specialist sooner.
- Insurance doesn't cover enough therapy but we can't pay for weekly visits out of pocket.
- His skin care medicine has needed refills and they have not responded to my calls. I am not sure if they do not want him using it until he sees a dermatologist or they are working on it or they just forgot.
- My child needs several medical interventions that he is not getting. This was a conscious decision by our family and our specialists, in order to avoid accusations of overmedicalization that we felt to be more harmful overall, than receiving inadequate care.
- She gets a lot of necessary care but we no longer see specialists as often as they recommend. Some we don't see at all. Others have lengthy wait times and we are looking to transfer to adult providers. Medical consultation becomes spotty. But mostly day-to-day needs are met.

FAMILY VALUES AND GOALS

93% FELT THEIR CHILD'S MEDICAL TEAM CARED ENOUGH ABOUT THEIR FAMILY'S VALUES AND GOALS OF CARE

ACCURATE ASSESSMENT

18% DID NOT FEEL CONFIDENT THAT THEY COULD RELY ON THEIR CHILD'S CARE PROVIDERS TO ACCURATELY ASSESS THEIR CHILD'S MEDICAL ISSUES

- Everyone is limited by their specialty and training and there is very little outside the box thinking. Everyone wants to provide some kind of recommendation, even if it is not a helpful / beneficial one.
- I wish the doctor could say 'I'm at a loss for how to be of help to your child. Maybe I could help you find another resource?' Not that I would stop seeing that provider, but that they could admit that their limited tools are exactly that: limited.

- My child cannot communicate, leaving us all guessing.
- My son is too complex for a single person to adequately assess.
- They are not well trained in his diagnosis. I feel like I know more than my primary care doctor.

RELYING ON PROVIDERS

13% DID NOT FEEL CONFIDENT THAT THEY COULD RELY ON THEIR CHILD'S CARE PROVIDERS TO ACCURATELY CARE FOR THEIR CHILD'S MEDICAL ISSUES

- Because of limited appointments and rescheduling of appointments, goals are not met.
- Our care providers admit that they are uncertain of how to treat my child's problems, as they are unfamiliar with his conditions.
- Some NEVER look at child's records, others have bias against some treatments.
- They are never up to date with my child's medical issues.

REFERRALS

10% DID NOT FEEL THAT THE REFERRALS THEIR DOCTORS GAVE THEIR CHILD TO SEE OTHER PROVIDERS WERE NECESSARY

- Mostly the referrals are made when they don't know what else to do. I can usually tell the difference between those we need for a reason and the rest.

PARENTS' MEDICAL ROLE

68% HAVE FELT THEY MUST ASSUME THE RESPONSIBILITIES OF MEDICAL PROFESSIONALS TO RESEARCH ISSUES RELATED TO THEIR CHILD'S CARE OR MEDICAL CONDITION

- A drastic medical procedure was suggested and we had to do all the research and ended up squashing the procedure but it is still being talked about.
- As the parent, the buck stops with you!
- Constant research is necessary, especially for rare conditions. I read medical journal articles and prescription fact sheets, talk with other parents in similar situations and ask questions on newsgroups.
- Every diagnosis my daughter has been given has been based on me questioning if she has the condition and requesting tests.
- I am always bringing treatment suggestions to my doctors because they don't know what to do.
- I am an expert on my child. My whole child. I bring that expertise to each specialist and only work with those who understand that.
- I am my child's best advocate, across the board, and the most knowledgeable when it comes to my child.
- I am usually more knowledgeable in recent innovations/advances concerning my daughter's condition. They are experts in their areas, but woefully uninformed about how their specialty interacts with other aspects of her needs/medical care. Even when it significantly overlaps!
- I don't mind doing this. I think my child benefits from me becoming as informed as possible so I can collect relevant data to help develop a treatment plan.
- I ended up enrolling in a college with a medical school attached so that I could have access to medical books to help search for answers as my daughters health has gotten worse. I am also the one that

brings studies to doctors' appointments to see if I can have an explanation or support in searching down different avenues.

- I found a natural way to control my son's spasticity. Two doctors wanted to do invasive surgery and add drugs to control it. He is now drug and spasticity free.
- I just finished 3D printing a modification to my son's tracheostomy speaking valve because on-the-market options were incompatible with his HME.
- If we can care and treat our child at home as opposed to a trip to the ER, we would prefer to do that and treat it before it requires hospitalization.
- I feel very strongly that I must educate myself with regard to my child's medical condition/diagnosis as well as all the services/medical procedures to treat condition. So yes I assume that responsibility and hope and expect the medical team is doing the same.
- Research helps me form appropriate questions. I have found that good questions pushes the specialist to continue thinking beyond the typical response he might give and leads to more thorough examination.
- That's how I saved her life.
- Things like fever of unknown origin. I researched possible reasons and my doctor checked all of those possibilities and found nothing. But at least she listened to me.

41% HAVE ACCEPTED A TREATMENT PLAN THAT THEY DIDN'T THINK WAS BEST FOR THEIR CHILD

- Doctor insisted child still needed to be fed via g-tube and I felt forced to accept their plan because my child was not gaining weight and I was concerned with is overall health. But, once it became clear that the doctor was just 'checking the box' without looking at the child as an individual, I made my own decisions.
- I felt like if I didn't follow through and try medication suggested that specialist would not continue to try and help or worse yet decide I was neglecting my child for not giving recommended treatment.
- Had a lot of specialists in a variety of fields telling us to do a procedure that did NOT feel right to me or my husband. We eventually caved and I still regret it. Procedure did not have desired outcome and in fact created additional problems.
- I have allowed biopsies, blood work and infusions that I thought were unnecessary because they kept being redone. Finally, put a stop to that.
- I have filled a prescription for a med, gone home to do some basic research, and then not given the med. This is about as far as we have gone in accepting a treatment we didn't think was best. Most of the time we say 'no' or 'we will think about it' up front.
- I have tried things that I didn't necessarily think would work, but didn't want to not give it a try.
- I was desperate and the doctor made it sound like the only solution. I felt that if I didn't agree he would say that I was a bad parent and quit treating my daughter. I ended up abandoning him as a doctor because of his mistreatment and misguidance.
- My daughter was given a G-tube. I did not agree that it was necessary, but was too new to the whole process to disagree effectively.
- Our son was given a tracheostomy against our wishes. We went in for some testing during which they proposed the trach as a potential treatment option. The test caused complications and then they refused to release us without a trach.
- Recently was sent home from ED when I believed we could not care for him at home and actually ended up admitted to the hospital about 5 hrs later.

III. PARENT VOICES

In the second survey, parents were asked to share their wisdom, concern and experiences with other parents. The information and insight was amazing. Angela Carosella, one of our project parent partners, compiled the following summary from the many pages of thoughts and suggestions provided by the parents in Survey #2.

PARENT THOUGHTS ON THE POSITIVE ASPECTS OF HAVING A CHILD WITH COMPLEX MEDICAL NEEDS

- Having a child with complex needs has given us a different perspective on life and family. It has brought us closer together and has helped us focus on what is really important—life!
- Our entire family has learned to appreciate the things other people take for granted. Each day begins and ends with a smile and a hug and you can't beat that! It's not about how big or fancy our house is, but about sitting around the dinner table as a family.
- Our family has clarified its priorities, deepened our relationship with God, and even changed careers to reflect what we have learned by caring for a child with complicated medical needs.
- The experience has strengthened our marriage. I have become a better parent-partner because I value my marriage so much more than I think I would have otherwise. It has made me realize how lucky we are to have what we do have, even if it is challenging, it is worth every second of every day. I am so grateful at how well my husband and I work as a team and how much we support each other.
- This experience has helped his siblings mature by appreciating the simple things in life. It's not about winning the soccer game but about the ability to run. It's not about wearing the trendiest fashions, but about having the simple freedom to dress yourself. It has also given my children a greater sense of responsibility. They are far less selfish than their peers, more mature and certainly more patient.
- It has brought out a passionate side of me that I didn't think I had. I now have an appreciation and empathy for other families with special needs children. It has made me accept help from family and friends, which was something I always said "no" and has also made me more generous in offering my help to someone who may be struggling with their child.
- This experience has helped me find the strength beyond what I ever imagined was possible.
- My son has a zest for living and a tenacity that often stops me in my tracks. He slows me down and keeps me in the moment. He has taught me unending patience and he motivates me to give my very best to everything I do.
- My son has to work so very, very hard physically, socially and academically. His days are long (much longer than mine) but he gets through each and every day with a smile. I think about his resilience and good sense of humor when I'm feeling overwhelmed or tired or just bored with my routine and it springs me right back to life! He simply brings out the best in me!
- I have developed intense dedication, perseverance, and fortitude. I can see beauty in small steps! Slower is not a bad thing. I am a stronger person.
- It has made me value doctors, nurses and therapists in a way that I never would have thought possible. I am much more patient when dealing with medical professionals and I have learned so much that I can share with others. I also have a much deeper respect and appreciation for teachers and even health insurance. Thank you Mass Health!!!
- I have become more organized—don't put things off since you don't know what might arise or when.
- I have met some truly amazing people and have become friends with a more diverse group of people.
- I love how everyone thinks I am such an awesome mother. Makes my day, every day.
- I was very career focused before this but this experience has led me to a different career path—one of patient advisory and advocacy. I have strengthened my leadership skills and I now have a job that serves a higher purpose. Because of my personal experience, I can offer real support to other parents rather than a clichéd "hang in there" when they are feeling low.

PARENT THOUGHTS ON THE NEGATIVE ASPECTS OF HAVING A CHILD WITH COMPLEX MEDICAL NEEDS

- There is not a “negative” aspect to having a child with complex medical needs. It’s my new “normal.”
- Overall, I can’t really think of too many negative aspects. Is it extra work, yes! But, I have learned so much about myself and about life. My son is the strongest little fighter I know. I know. I wouldn't want to go through what we went through again with another child but I honestly can't say that it has been a negative experience, even with some of the really crappy things that have gone on.
- Knowing that he will never be normal. This makes me sad, but he wakes up with a smile on his face every day. I don't see my situation as a burden it is just the way my life is.
- Caring for our complex child is very hard on our marriage and family life. We cannot get away or do things as a couple so we always try to do things as a family. But because our child is very sick, his needs need to take priority and even coming together as a family is often difficult.
- We simply do not have the freedom to live our lives. We are always changing plans at the last minute, making it very difficult for child care, never mind maintaining friendships.
- As a single parent with no family support I experience a stress level that I did not know was possible. I have very few people who I can count on. I am labelled as “different” and have lost friends and family due to the needs of my child. I feel very isolated and alone. I don't expect everyone to understand all of my child's medical details, however not making me feel bad because we have to live our lives differently would go a long way.
- Employment opportunities are limited. I always need time off from work which has curbed my professional advancement which in turn, has negatively impacted our family’s finances. This has put a lot of pressure on my spouse and has been a drain on our long-term financial stability.
- I feel as though I never really move forward because in many ways, I have an infant that will not mature. Yet, as my child gets older our challenges seem to increase and we need to think about her future, making certain that we can provide for her even after we are gone. This forces us to have difficult conversations and to face issues that we don’t want to even consider.
- Because of what our child experienced, we limited ourselves to one child. This was a difficult decision for us to reach especially since we firmly believe that our son would progress a lot quicker if he had siblings—peers who would challenge and motivate him but at the same time be gentle and understanding of his needs.
- We are moving closer to my child’s doctors to decrease car time get some type of life balance. Unfortunately, we will now be farther away from family and friends and many of those relationships are already stressed.
- Since I lost my husband, I need to work full time in a demanding position and it is exceedingly difficult to 'keep the boss' happy and I’m sometimes forced to play the FMLA card. I have found that I am much more outspoken, harsher, less patient, and less tolerant of other’s mistakes.
- Nothing is simple, everything from ordinary everyday things like eating, walking, and talking to buying them a swing or a bike or how they sit in the car is difficult.
- The medical condition is always in the back of my mind, and every fall, trip, nosebleed gets evaluated in a different frightening way. I get jealous of what other kids can do so easily then feel guilty because I know other families who are far worse off than me.
- We live with the spiritual and emotional weight of knowing that our child will die before adulthood.
- I have forgotten how to be the positive person I always thought I was. I do not have the energy or desire take care of my own health. I am woken up multiple times each night by alarming medical equipment. I have become obese and suffer from anxiety because I don’t know who will take care of my child if something happens to me.

PARENT COMMENTS TO OTHER PARENTS

- Second opinions save lives! Don't let a doctor make you feel dumb or not able to go get another opinion.
- Acknowledge that practicing medicine is an art and that there is a learning curve for physicians. Go to a teaching hospital or major medical center if possible, they are used to dealing with complex patients and then be patient. It is an ongoing process. Learn how to navigate the system and never be afraid to ask for help.
- As parents, we try and do everything we can with our son just like every other family. We travel, go to concerts, the beach and sports events. With a little planning, you can do anything you want with your child. Don't be afraid of getting out in the public, people will get more out of seeing your child enjoying life than you can imagine.
- Love yourself and act on it. You need you and so does your child. Value yourself. Take 5 minutes to listen to music you like, burn a favorite candle, do something that is life giving not life taking. Be grateful for any steps of progress that are made. Do not compare (very hard I know).
- It could have been much worse. Enjoy the simple moments with your child. Stop feeling guilty!!
- Just remember that underneath all that medical complexity is a child wanting to be loved and nurtured. A little bit of love goes a long way. Cuddling and being silly are an important part of our day, one that is never skipped in our house.
- Raising a child with special needs is very hard, but there are people that have come into my life that I never would have met. It is important to live for today.
- Sometimes simply repeating the phrase, "that's not acceptable" over and over is more effective than pleading and explaining—it's clear and expresses exactly what you are feeling. Learn about every resource in the area, even if you don't think you need them. A good relationship with the nurses in your doctor's office is essential. They can get things done.
- Take advantage of people who are truly willing to help. When you have a sick child you will see who your true friends are. Although dinner invitations and offers to babysit may not be practical ways to "help" you where you really need it, this is the only way people with "normal" lives know how to extend a hand. Think about what you really need—a couple of extra hours of sleep? Maybe a friend or relative can come over for a few hours while you nap or take a bath or even read a book. Don't feel guilty.
- If you are not a single parent and you don't get enough sleep try this: each one of you pick a day on the weekend when you can sleep in while the other parent takes care of the family. Getting sleep at least once a week saved our lives!
- Know that you are doing a great job for your child. I always tell my students "I don't want perfect, I want your best." Remember, perfect is not really a thing.

PARENT COMMENTS TO DOCTORS

- Trust that parents of children with complex needs know what they are talking about. Treat them as part of a team, ask their opinion and don't be afraid to tell a family when you don't have the answer. It's ok that you need to do some research or check in with another doctor. We will respect you for that (as long as you actually follow through!!)
- You all know the textbook case. Parents know how to live with the constellation of illnesses and symptoms on a daily basis. You know the surgery and the meds. We know the adaptive strategies. We could be good teammates, but often, parents don't feel respected. They feel they have to defer to docs and other medical professionals. Why? We each have our areas of expertise. Why not work together?
- Listen to parents and respond to their concerns. Be humble, do not lecture. The parent of a special needs child needs you to understand and be empathetic and sometimes this means "decoding" what

we are trying to say. Parents are usually in the dark and you may be their only hope. Don't treat us like a nuisance. Before you say anything put yourself in our shoes.

- Don't underestimate me. I am an intelligent human being, even though I am unkempt and sleep deprived.
- Build in more effective case management and psychosocial supports into your medical care services. Families with complex kids often need to talk.
- By the time our kids reach the doctor or the ER they are sick and fragile. And so are their parents. The whole family is in crisis. Everyone is exhausted, hungry, thirsty, and may have been up for hours. Sometimes family members are overwhelmed and, possibly, not on their best behavior. Have some empathy. When our daughter was recently admitted, the nurse offered my husband and me a cup of water and a chair. I was so grateful, I felt like crying. Don't rush to judge me as an unreasonable person when you don't know the situation.
- If you don't remember the exact details of the visit please don't guess when writing your clinical note. Don't sign off on a residents note without making sure it is 100% accurate picture of the visit. Don't copy and paste from older notes or worse yet, from other patients' profiles! There is nothing worse than seeing another child's name in my child's medical record.
- Please don't assume parents are fine just because we look like we are coping. Remember that some of us are just one more medical emergency away from despair.
- Remember that the child is the patient. While the parents may be making the decisions or involved in the process it is the child that is sick. When you have a child that is aware of what is going on they want to be involved in their treatment. Talk to them in terms they will understand and remember that although they are sick children they are still people, so treat them like you would any other person.