

FRANCISCAN HELPS FAMILIES CONNECT

PCORI PARENT ENGAGEMENT PROJECT

SUMMARY OF RESULTS OF SURVEY 1

This report contains a summary of the responses parents provided in Survey #1. We are grateful to the **121 parents** who completed our first survey and shared very important information about caring for their children with complex healthcare needs. 75% of the survey participants were from throughout Massachusetts representing different healthcare systems; the remaining 25% were from other U.S. states.

Survey #2 will be emailed to you in late May. This survey will build on issues parents identified in Survey #1 as well as new topics requested by the parent participants.

We cannot thank you enough for your responses. Please be sure to complete Survey # 2 – it will contain 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!
Parents who want to join our project can enroll at:

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 59 pages of information in Survey #1. We have tabulated and summarized the parent responses for you in this report. Here are some key highlights from Survey #1.

- Most parents reported **communication problems** with their child's healthcare providers, particularly with their child's medical specialists.
- Most parents **did not feel comfortable disagreeing** with their child's doctors.
- Many parents had problems **dealing with insurance companies**.
- A small number of parents had a plan in place for their child's care once **their child becomes an adult**.
- Most parents were **satisfied or very satisfied with the quality** of their child's medical care.
- Most parents **spent a great deal of time** scheduling doctors' appointments, communicating with healthcare providers, and interacting with medical supply companies.
- Most parents reported feeling stressed or overwhelmed and many reported feeling isolated.
- Parents identified many issues that cause them to feel **stressed or overwhelmed, including:**
 - Getting their child's healthcare needs met without resistance from providers
 - Dealing with insurance and getting necessary supplies
 - Getting good nursing and PCA care
 - Concerns over their child's safety and long term care
 - Impact of constant care
- Parents identified two main issues that cause them to feel **isolated**, including:
 - Lack of support from and disconnect with their community
 - Lack of freedom

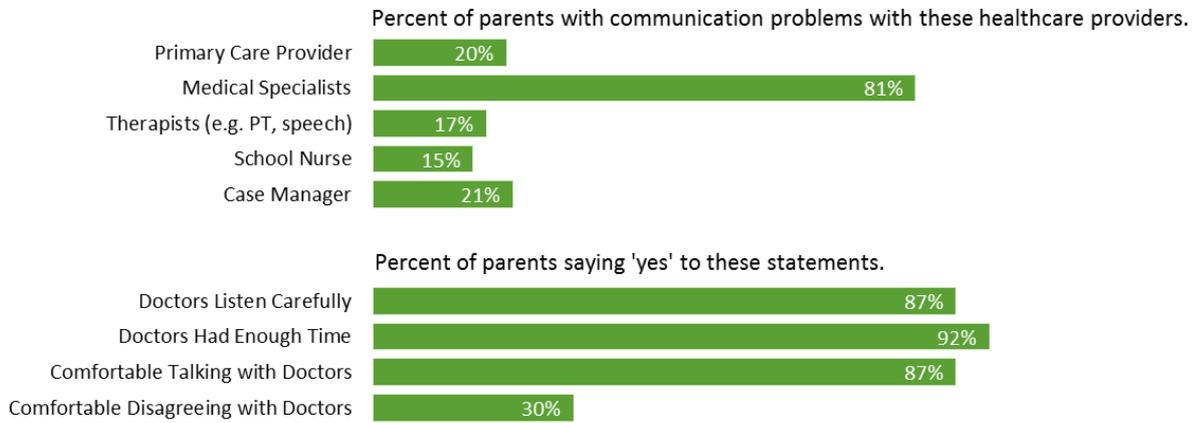
Thank you for your responses!

We look forward to hearing your voice in Survey #2 when we address many new topics!

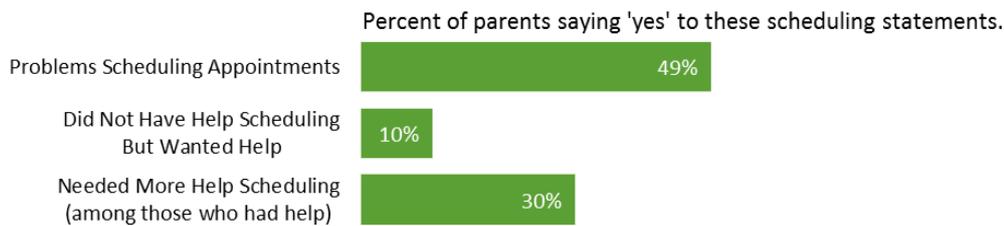
II. TABULATED SURVEY RESULTS

COMMUNICATING WITH YOUR CHILD'S HEALTHCARE PROVIDERS

30% of parents reported problems with communication among their child's doctors.



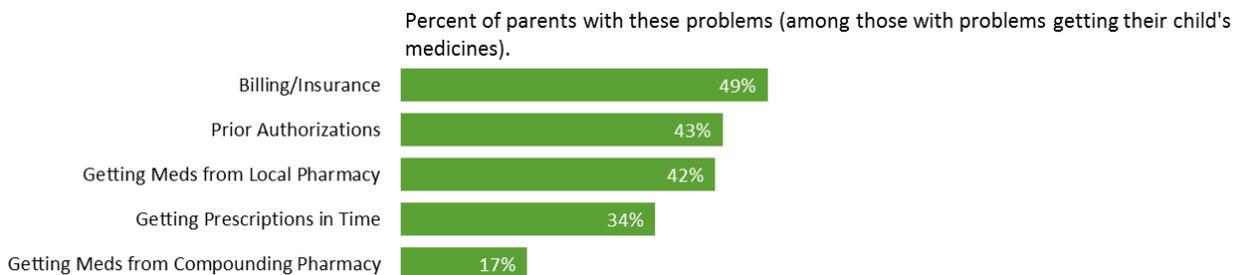
SCHEDULING YOUR CHILD'S APPOINTMENTS



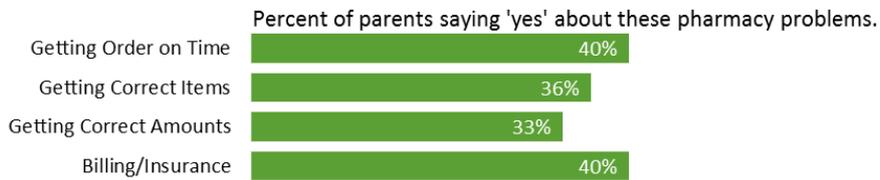
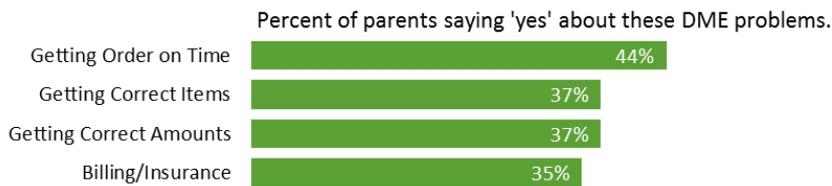
CARING FOR YOUR CHILD AT HOME

29% of parents reported problems transporting their child to appointments.

48% of parents reported problems getting their child's medicines and 44% of them said it affected their child's health.



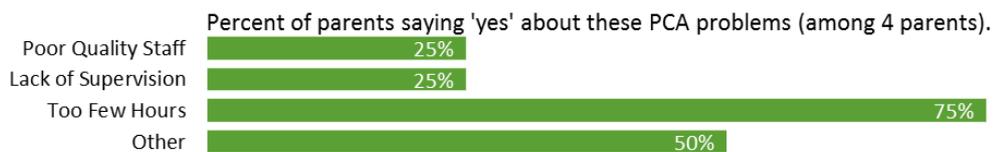
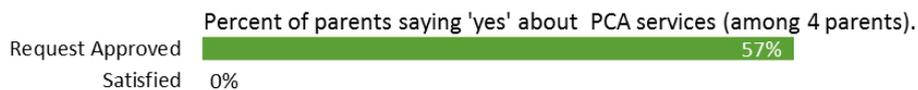
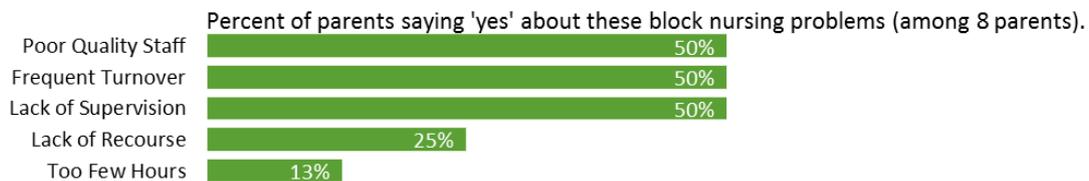
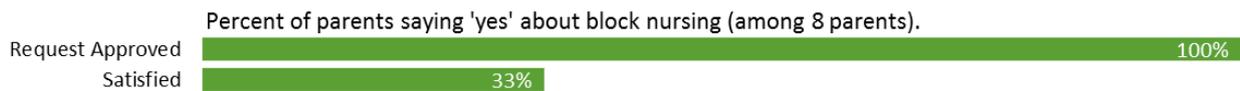
46% of parents reported problems getting their child’s medical supplies.



31% of parents with DME or pharmacy problems reported that the problems affected their child’s health.

34% of parents with DME or pharmacy problems reported having to reuse supplies intended for single use.

47% OF PARENTS REPORTED PROBLEMS GETTING OR COORDINATING HOMECARE SERVICES.



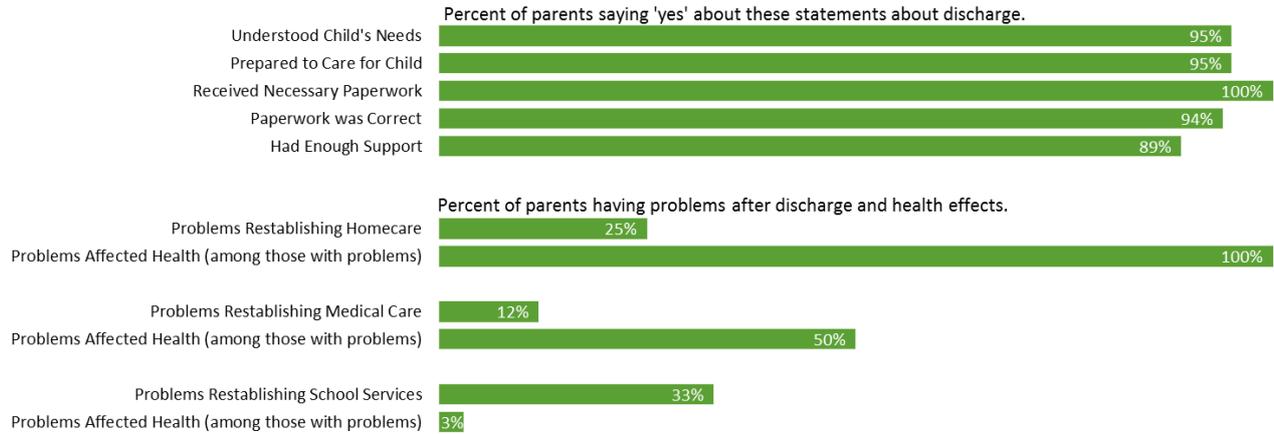
32% OF PARENTS REPORTED PROBLEMS FINDING HEALTHCARE PROVIDERS

Many parents wrote about:

- lack of doctors near their home experienced with caring for medically complex children;
- lack of nearby specialists;
- long wait times for appointments; and
- lack of experienced nurses or PCA’s for homecare services.

CHALLENGES AFTER A CHILD’S HOSPITALIZATION

24% of children were hospitalized in the past 3 months.



64% OF PARENTS REPORTED PROBLEMS DEALING WITH INSURANCE COMPANIES

Many parents wrote about:

- difficulty getting prior authorizations;
- time spent trying to get prior authorizations;
- insurance denials of medically necessary medications, equipment and medical supplies;
- frequent billing errors; and
- poor communication with insurance companies.

40% OF PARENTS REPORTED MEDICAL NEEDS THE SCHOOL NURSE DOES NOT PROVIDE

Many parents wrote about:

- the need for 1:1 nursing for children with a tracheostomy or who are ventilator dependent;
- schools not having a full time nurse;
- nurses not equipped to deal with the child’s complex medical needs; and
- children not being allowed to attend school due to lack of (qualified) nursing care school.

PLANNING FOR ADULTHOOD

Percent of parents with a care plan in place or intent to plan for adulthood.



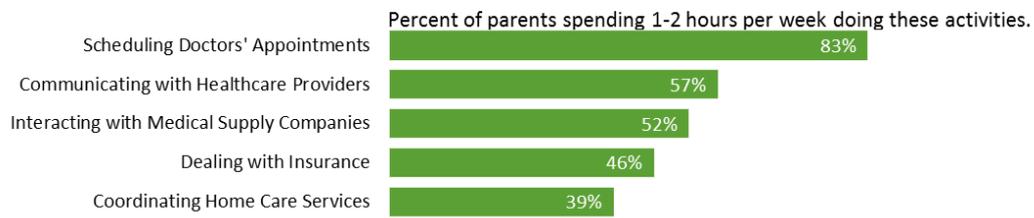
OVERALL HEALTHCARE EXPERIENCE

83% of parents were satisfied or very satisfied with quality of care.

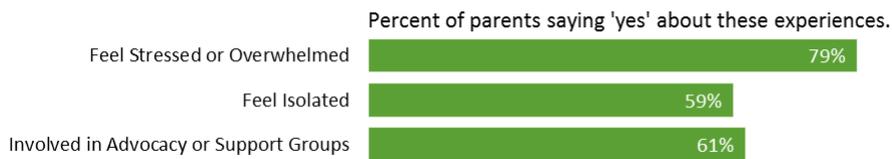
31% of parents were concerned about being labelled a helicopter parent.

58% of parents know where in the system to get help if they have problems that can’t be resolved with their doctor.

TIME SPENT MANAGING CARE



YOU, THE PARENT CAREGIVER



III. STRESSED AND OVERWHELMED: ISSUES AND RECOMMENDATIONS FROM OTHER PARENTS

GETTING OUR CHILD'S HEALTHCARE NEEDS MET WITHOUT RESISTANCE FROM PROVIDERS

Lack of confidence in our child's diagnosis is a major cause of stress for our family. Managing multiple providers who do not fully understand our child's condition, who do not communicate with one another, and who often disagree over care or root cause of symptoms puts an overwhelming burden on us as parents to try to bring all of the pieces together. When we try to understand the reasoning behind medical decisions, we are all too often belittled or rebuked to the point where we refrain from asking questions for fear that we will be criticized for how we manage our child's medical care. The fear that something critical has been missed because we didn't ask enough questions or push just a little harder is absolutely crushing.

Finding the right doctors is only half the battle—coordinating care between the medical team is impossible. A doctor's appointment is not a single event. We need to prepare for days, sometimes weeks to research and to make sure we ask the right questions in the right way so that we can make the most of each visit. Following a visit, we need to be super-aggressive in getting a copy of the doctor's report or clinical note and to schedule ordered tests, which can never seem to be scheduled within a reasonable time frame.

Rescheduling an appointment is never an option because it can take up to 6 months before we can get another appointment. This means that often times we need to make difficult decisions like taking our child out of the house when he is sick just to be seen in a timely manner.

DEALING WITH INSURANCE AND GETTING NECESSARY SUPPLIES

The stress comes from reoccurring problems that never get fixed because staff is poorly trained and never seem to "close the loop". We are forced to make the same calls over again and to accept long phone wait times to get in contact with the right person. Solutions are temporary and this is an across-the-board problem with insurance companies, pharmacies and homecare companies. After 14 years of requesting the same items every month, we have NEVER received a correct order from our DME and things get worse every month. We are constantly worried about running out of supplies and often have to reuse supplies intended for single use just to make sure we always have a reserve.

Agencies do not seem to care that our children are in need of life-sustaining supplies. Medical items are constantly denied and we are required to tolerate lengthy appeal processes which never get resolved or by the time they do, our child's needs have changed and we no longer need the item that we were fighting for.

NURSING CARE AND PCAS

The inability to find experienced nurses and quality homecare that can manage complex and urgent care is a major stress. Agencies (including Mass Health) are unorganized and staffed with inexperienced people. PCA and PCW hours go unfilled and managing the schedules of all the people that come into our home is overwhelming. We do not have confidence in many of the nurses who are assigned to us and worry about having people in our home who fall asleep, surf the internet or text their friends when they should be watching over our children.

We are often forced to accept inexperienced and unprofessional nurses and there is little recourse when there is a problem. We were sent a nurse from Mass Health to care for our vented child. She did not know how to use an Ambu bag or perform an emergency tracheotomy change. Thankfully, we had been trained and we were home when our child started desaturating. If we had left this woman alone, our child would have died. When we called Mass Health to complain, we were told that while we could file a complaint, unless we could actually prove that the child suffered harm, there was nothing they could do—they would not even speak to the nurse about the situation claiming that "a lot of parents exaggerate" and it would be difficult to address each case. We fired the nurse but in doing so, accepted

the full responsibility for caring for our child who had only been home for a few days which was very scary. These problems often continue because the parents are just too tired to fight.

CONCERNS OVER CHILD SAFETY AND LONG TERM CARE

Just keeping our child safe is often very hard to do. Our child frequently has episodes of extreme behaviour and rapid medical shifts including seizures that can last for hours. Our child often struggles during transfer and he is strong. When he's angry he becomes aggressive and we fear that he is a danger to himself and to others. We are concerned with our child's long-term medical prognosis especially when he gets older. Although we are trying to get him to participate in his own care, he needs constant supervision and we worry about where he will live as an adult and who will care for him when we are no longer able.

We are concerned about the impact our child's health care situation has on our finances. We are dependent on one income and this puts a lot of pressure on my spouse. We often struggle to find the money necessary to travel to out of state appointments.

We do not have enough space in our house to accommodate our child's needs and do not have the finances to afford a larger house or make renovations to accommodate the needs of our entire family.

THE IMPACT OF CONSTANT CARE

The constant care required by our child is overwhelming. We often feel that we are failing her and that we are not doing enough to further her development. We sometimes feel that our situation is hopeless and struggle to keep going. There is so much to remember and to coordinate and since our child does not seem to be making much progress, we are concerned about the perception others may have about our parental abilities.

I am the sole caregiver for my child and so fearful of what will happen if I forget to communicate what one specialist says to another. I worry about medication side effects or the consequences of interaction if I don't research and cross reference medications prescribed by other doctors. This is a lot of pressure for one person who is not medically trained. Doing this as a single parent (widow) is so very hard. I need to work at least part time to support our financial needs, but I feel terrible because I know my son needs me at home. Sometimes, I cannot get him the care he needs but I cannot miss work.

The complexity of our child's medical needs and the ICU level of care we have to provide him with daily means we need to work around the clock. Our child requires 24/7 supervision and we are required to have a live-in aide which means no privacy for the rest of our family. The relentlessness of running an ICU at home while trying to give our other children some sense of normalcy is absolute exhaustion and we feel constant anxiety of the unknown.

All of our free time is spent coordinating our child's care and there simply are not enough hours in the day to do the things that would benefit her overall health such as exercising or socializing in the community. She is completely dependent and just the physical aspect of taking care of her and dealing with her moods has taken a toll on our entire family. We are unable to get out as a married couple. We don't have any time to unwind or to calmly think about and plan our family's future. We do not spend enough time with our other children nor can we support them enough with school, sports, etc. and this adds additional stress.

We are on a constant sick plan to limit the risk of pneumonia so we do not socialize with other families. I can't just put my daughter in the car and run to the store or go to the mall and too often, we are forced to stay home. My child has not had any of the experiences that typical children her age have had and I worry that this lack of socialization will further impact her overall development.

WHAT WOULD HELP YOU FEEL LESS STRESSED OR OVERWHELMED?

- A single point person to coordinate care
- Physicians working as a team; finding ways to share information and to agreeing on how to treat the *whole* patient
- Not being solely responsible for conveying information to physicians and specialists
- The opportunity to review physician notes for accuracy; requirement for parent sign off before a note is entered into the file, and providing parents with copy at the end of a visit, similar to a discharge note
- The opportunity to meet and make friends with parents who have children with similar difficulties
- Reliable transportation
- Summer services
- Sleep
- Time to reconnect with my spouse
- Nutritional support—there are too few resources for diet and nutrition. GI doctors ARE NOT the answer
- Help with IEPs and financial assistance for when an advocate or attorney becomes necessary
- For Mass Health to have accountability and better screening of their nurses
- Quality nursing support: backup plans for every patient, reliable substitutes for complex cases, more nursing hours, competent nurses that will stay awake to watch my son at night so I can sleep
- A babysitter we can trust
- More money
- If I didn't have to work
- More financial options for middle income people who want to work
- More fulfilling opportunities available after turning 22
- More readily available home services such as quality respite care
- Connection to my community; being able to go to church regularly and engage with a spiritual community
- A better insurance system
- If my child could make friends
- Having time to exercise and take care of my own physical and mental health
- Not always being in “therapy mode”—allowing my son to be a kid, to play and goof off without the fear of falling behind
- A program where my mom could get paid for caring for my son. She is fully trained in my child’s care and is more reliable and experienced than most nurses we have had but I cannot afford to pay her.

IV. ISOLATED: ISSUES AND RECOMMENDATIONS FROM OTHER PARENTS

LACK OF SUPPORT AND DISCONNECT WITH COMMUNITY

My family is too far away to help and I can't leave my child with just anyone. The lack of reliable, qualified help prevents us from going out and connecting with our community.

I don't leave the house except for medical appointments. I have no outlet or personal identity. I am unable to take a part-time job or volunteer.

We are disconnected from our spiritual community because we are not able to participate on a regular basis and we are unable to socialize as a couple.

We don't know another family who has a child with the severity of disabilities, complexity of medical needs, and heightened fragile condition as our child and so we don't have anyone who we can really talk to, anyone who understands.

My child is frequently hospitalized and admissions range from a few days to several months. As years pass, I find myself with less and less friends and family support. My husband and I are totally independent of one another. He does his thing at home with our other son while I am at the hospital with our sick child. Divide and conquer, it's the only way to manage but there is nothing left of our marriage and that is isolating too.

Others don't understand how much preparation everything takes or that it may take years for my child to learn to do something that a typical child can pick up in an afternoon. I feel like I am a one-person cheerleading squad for my son and I'm constantly being patronized by people who say things like "you are a special person" or "you are a saint". It drives me crazy!

The inability to participate in school or community programming because there are no modifications in place to fit my child's needs is very hard.

My child goes to a public school and while they are very good with her needs, she is the only one with her profile in the school. I have very limited connections with any other parents in the system and feel like I need to figure out every step of the process on my own.

I feel I am the only one who can handle and coordinate my child's needs. My spouse cannot organize, keep notes, or follow up as much as is required. Also, my spouse is not a good judge of what is emergent and what is not.

LACK OF FREEDOM

The inability to leave the house for more than a few hours to run errands or grab a coffee is very stressful and people do not understand why. Family and friends sometimes come to visit but they are not comfortable with my child's medical issues. We don't see them often and it is very hard for them to relate to the challenges and needs of a medically complex child who is total care.

My child cannot do most of the things that "typical" kids do—she has poor balance, does not eat on her own and cannot be near pets or sick children. This makes play dates nearly impossible. Her gross motor skills are slow and she is always trailing behind other kids and frankly, this breaks my heart, I'd rather stay home.

Friends get tired of always coming to my house and working around my scheduling restrictions due to my child's needs. Her medical instability makes it difficult for me to plan ahead or to commit to anything and while I feel that my friends care, they cannot relate and eventually, they just quit trying to connect.

I have been unable to leave my rural area because school calls nearly every day with a medical issue or emergency. I'm afraid I will be 45 minutes away and he will have a medical crisis. This means I can't buy groceries, go to my own medical appointments or visit friends while my child is at school.

Fragile health and bad weather—snow and ice makes it difficult to get about when you are wheelchair dependent.

WHAT WOULD HELP YOU FEEL LESS ISOLATED?

- My ideas of God have changed and sometimes that makes me feel isolated because others don't get that or they just don't accept that that is ok
- Knowing more people who share our financial stresses
- More inclusive programming
- Freedom to just get out and do something—anything
- Working outside the home
- Interacting with other adults; being able to talk to someone at my level
- If my friends and family understood more and I had a better support network
- Friendships with families in similar situation
- Finding and joining a support group
- Family counselling/ therapy sessions
- An on-line community. Parents like me rarely have the time or flexibility to physically meet up for support groups
- Getting away for a few days
- Being able to get out and do things as a family
- Awareness by others in my life that they can help and reach out to support
- Finding reliable and professional care for my child so I can take a vacation with my spouse
- I just want to be a regular mom—I want to share my child's experiences without people feeling like they have to comment on my “heroic efforts”
- A residential facility that is closer to home; access to beds

V. PARENTS SHARING THOUGHTS WITH OTHER PARENTS TO MAKE A DIFFERENCE

In the first 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 #1.

STAY CONNECTED

Seek help; brainstorm with anyone willing to listen. Get involved with organizations that advocate for your child's disability. Support groups, church groups, adaptive camps, foundations and social media groups are all great resources. Every child is different and every family has their own set of challenges and difficulties, however, complex health issues carry their own culture of community. By getting involved, the day-to-day normalcy of the every single thing we do is shared in meaningful ways.

Educate yourself on your child's rights; familiarize yourself with the law and the various governmental/social departments that can help you. The older your child gets, the harder you will have to advocate for their needs. Make time to develop your advocacy skills, written and verbal communication skills, and listening skills. It will save you a lot of anxiety and stress in the long run. The more you know, the stronger you will feel and the more in control you will be. You will not be as frustrated and you will be a better advocate for your child!

Don't alienate your family and friends. Do all you can to help them understand your child's condition. Educate them so that they can help. Taking care of a child with complex medical conditions is daunting and scary for someone who is not used to doing it, even if it's just long enough for you to take a shower or sneak in a quick nap!

Volunteer at school so that the teachers know you and vice versa. You are more likely to deal with each other as human beings, not as rubrics or adversaries. This will make advocating for your child easier.

TREASURE EVERY DAY AND LIVE YOUR LIFE

Involve your children in community recreation and try to give them as normal of a life as possible. Do not let your child's illness define him. To the degree to which it is possible, involve your child with other children as they are truly the best teachers. Approach things from a quality of life perspective and share your voice—raising a concern can often help the next family that experiences the same issue.

Enjoy your child at each stage of their development. Don't waste time and energy worrying so much about what might happen in the future that you forget to enjoy some of the wonderful moments that are happening in the present.

Don't put pressure on yourself by setting deadlines for things to happen (getting a trach out, getting rid of g-tube, etc.). Many of these events are beyond your control and if those deadlines are not met, you feel that you are to blame. Let some of that go and focus on all the positive strides that are being made.

MANAGING YOUR CHILD'S CARE

Be assertive and trust your instincts! No one knows your child better than you. Speak up and advocate. If you don't understand something, have it explained until you do. And, if you have a different opinion let it be known. Doctors have gone to school, but YOU know your child!! If something isn't right don't stop!! Find doctors who respect you and do not be afraid to change doctors if they are not supporting you. You CAN do something about it!

Set ground rules with home nurses at the beginning. It's much easier and less awkward than to try to correct things after the fact. Keep a journal to write a summary of each appointment so you don't forget anything they said. It's also a good outlet to process information.

Ask your primary care physician or a specialist you trust if he/she would be willing to serve as the communication point – it can save a lot of legwork and phone time and it helps to minimize miscommunication.

Create Child Care Sheets with checks to mark care that should be done as well as space for notes on additional items done is invaluable for ensuring all care is done and in a timely manner. Helpful for you, home care providers and also family/friends who may occasionally step in to help and are not experienced with the full day-to-day care of your child.

Keep a notebook for your child and update all his doctors, phone numbers, important documents, surgeries, procedures, hospital and ER visits, etc. Keep blank pages in the back to jot down notes, weight, blood pressure, etc. Track both medical and behavioural patterns. Take it with you to appointments and use it to keep an anecdotal record of all visits. This is helpful for anyone who is involved with your child's care—you can't keep it all in your head!

Always get a copy of records and tests because they are not always shared among providers, and read them carefully for errors.

Try to establish one contact person for insurance companies, DME, etc. Attach a photo of your child when you submit annual forms/applications. This will help to develop relationships with people that are willing to help you.

If your insurer has been paying big bucks for a rental for several months, find out the retail cost and call the rental company and ask what price they will give it to you for. Point out that your insurer paid the retail price several times over and they may even give it to you for free.

If you have exceeded limits for services, negotiate a self-pay rate. If out of pocket bills are too large, call the billing office as they are often willing to make an adjustment or give you a "discount".

Some electricity carriers offer a discounted rate to families with a disabled child who is on any low income program, receives Mass Health, or is linked with a program like Mass Commission for the Blind.

ENCOURAGEMENT

Stay strong, stay positive, advocate hard and don't give up. You are doing a **great job!** You are not alone. No matter how much you feel isolated or frustrated there are people who understand and will help you. It is okay to take time for yourself because if you don't take care of yourself you will not be at your best to help your child.

RESOURCES RECOMMENDED BY PARENTS

Massachusetts Family Ties—A network for families and professionals supporting children & youth with special needs. <http://www.massfamilyties.org> and 1-800-905-TIES (8437)

MA Federation for Children with Special Needs—Provides information, support and assistance to parents of children with disabilities, their professional partners, and their communities. They also offer training for educating family and friends on your child's disability and needs. *fcsn.org* and 617 236-7210, 800 331-0688

Courageous Parents Network—Provides parents and families of children (ages 0-18) living with serious illness with expert guidance and virtual community to promote coping and resiliency and to lessen the isolation they experience. www.courageousparentsnetwork.org.

Pass it on—Assists families who fall through the cracks in the healthcare system and do not have the healthcare coverage or funds to acquire items needed to improve their child's quality of life. They provide free recycled durable medical and assistive technology to children with disabilities up to the age of 22, and their families. <http://www.passitonforkids.org/> or 800-267-6768 and 508-477-6966

Oak Hill (Connecticut) also maintains a list of used equipment for purchase at a fraction of retail cost. <http://www.ciboakhill.org> or **860 242-2274**.

Charles River Community Boating (Boston)—Universal Access Program offers accessible sailing through the Universal Access Program for individuals who require special assistance. <http://www.community-boating.org/programs/universal-access-program> or 617 523-1038

VI. PARENTS SHARING THOUGHTS WITH HEALTHCARE PROVIDERS TO MAKE A DIFFERENCE

In the first survey, parents were asked to share their wisdom, concern and experiences with healthcare providers. As parents filled an additional four pages with their thoughts, Alexis Snyder, one of our project parent partners, summarized the parents' direct quotes. A key goal of this project is to share these comments with stakeholders in the healthcare community at the completion of the surveys.

CARE COORDINATION

Healthcare providers – please communicate better with each other about our children. Their medical needs are so complex and we need your help to get them the care they need. Parents feel that a care conference or coordination meeting would be helpful, but feel guilty asking for such a meeting. Parents are asking for help with coordinating appointments and getting referrals. One participant in particular stated that his/her child is seen by a complex care service but that they only receive referrals and phone numbers for specialist appointments and not actual help coordinating appointments. Others felt that their child did not have a “medical home” which would be helpful in coordinating appointments and facilitating communication between providers. And please give us written orders for home nursing, PT and/or OT in the community and/or school.

ACTIVE LISTENING AND COMMUNICATION

Participants expressed time and time again that they wished their health care providers would take the time to listen. We listen while you talk, please listen when we talk. We need you to help us with your knowledge.

We are the experts on our children. Please don't dismiss our concerns or a diagnosis just because our children are not in pain. Please look at the children as a “whole person” and listen to the children - they know their bodies.

Please take the time to familiarize yourself with our children before the appointment. One parent suggested a better database for providers to access information about the child. And although we are the “experts” of our children, please do not also assume that we know everything; we still need things explained in layman terms.

Please learn our children's communication styles. Just because a child may be non-verbal doesn't mean he/she doesn't communicate. Engage children by learning something about him/her that isn't medically related-use this to gain his/her trust and mine. The more I think you care about my child, the more I trust you. Treat them with compassion and respect-they understand more than you think they do.

EMPATHETIC CARE AND FEELING LIKE A TEAM MEMBER

Many parents are feeling misunderstood and disrespected and are afraid to be seen as a helicopter parent. They are frustrated with the healthcare system and feel that their child's school does not take their child's health needs seriously.

Many children are living with an invisible illness or disability or may not yet have a diagnosis. Please don't assume when you hear hoof beats that you have a horse, you may have zebra. Every child is an individual and what applies to one child, may not apply to another.

We are the experts of our children, not the enemy. Please have patience with us. We are stressed. We are scared for ourselves and scared for our children. Forgive us if we sound rude, we are not perfect and we are tired. We want our children to live the best potential life and have the best possible care. It is OK to tell me you do not have all the answers, just please don't give up.

We are not perfect, but you have absolutely no idea what stress we are under. We also have lives, have to go to work, go shopping and take care of other things just like you. We have to go home to a child who we absolutely adore and love; however, he/she will never grow up and leave the house to move on to better things.

Please make your approach more personable and do not be judgmental. Please value and respect us, we are more engaged when we feel like your partner. The best doctors on our teams are the one's that value our opinions and ask us

what we think. We need to be part of the decision making process and the care team. Please remember that the decisions you make affect our entire family.

SUPPORT

Parents are looking for help and need your support – please don't assume that we have help. Please take the time to ask us how we are doing: "Anything you can do for us is for the health of our children". Parents need reassurance that we are doing a good job and need recognition for their hard work. Parents also need help with their children's transition to adulthood.

Please give us more resources. Please take the time to learn about what resources are available to us and familiarize yourself with what you are recommending.

Please be considerate of our time and don't schedule any unnecessary appointments but give us more time with each visit. Travel time can be a big factor - please understand this if we need to decline an appointment it's not because we don't care. Emails and phone calls are life savers.

If you are a therapist coming into our homes, please don't make recommendations outside of your expertise. We understand you are trying to help but it sometimes leads to extra unnecessary appointments to rule out a concern.

It would be easier if we didn't have to fight for everything we need when it comes to insurance coverage.

School nurses are overwhelmed and need more support, especially in the classroom.

RECOMMENDATIONS FOR A MORE "USER FRIENDLY" OFFICE VISIT

- Additional or adequate accessible parking
- Weekend and/or late night appointments
- Written materials and resources
- Less paperwork! Please don't have us fill out forms that don't pertain to our child, such as a developmental questionnaires asking about milestones our child will never reach – this is very upsetting.
- Changing area for larger child/older child/teen who wears diapers
- Accurate billing – inaccuracies cause parents to spend hours on the phone with insurance providers and billing offices.

HERE ARE SEVERAL RESOURCES RECOMMENDED BY SURVEY PARENTS

[Massachusetts Family Ties](http://www.massfamilyties.org)—A network for families and professionals supporting children & youth with special needs. <http://www.massfamilyties.org> and 1-800-905-TIES (8437)

[Federation for Children with Special Needs](http://www.fcsn.org)—Provides information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. They also offer training for educating family and friends on your child's disability and needs. [fcsn.org](http://www.fcsn.org) and 617 236-7210, 800 331-0688 (in MA)

[Courageous Parents Network](http://www.courageousparentsnetwork.org)—Provides parents and families of children (ages 0-18) living with serious illness with expert guidance and virtual community to promote coping and resiliency and to lessen the isolation they experience. www.courageousparentsnetwork.org.

[Pass it on](http://www.passitonforkids.org/)—Assists families who fall through the cracks in the healthcare system and do not have the healthcare coverage or funds to acquire items needed to improve their child's quality of life. They provide free recycled durable medical and assistive technology to children with disabilities up to the age of 22, and their families. <http://www.passitonforkids.org/> or 800-267-6768 and 508-477-6966

Oak Hill (Connecticut) also maintains a list of used equipment for purchase at a fraction of retail cost. <http://www.ciboakhill.org> or 860 242-2274.

[Charles River Community Boating \(Boston\)](http://www.community-boating.org/programs/universal-access-program)—Universal Access Program offers accessible sailing through the Universal Access Program for individuals who require special assistance. <http://www.community-boating.org/programs/universal-access-program> or 617 523-1038.