We are grateful to the 114 parents who completed Survey #5 and shared very important information to fill in the gaps in what we learned from the first 4 surveys.

The information parents have shared has been amazing – and it WILL make a difference!

When citing or using any information contained in this document, please use the following citation:


For more information about this data or to discuss collaboration opportunities, please contact: Carol Nash at CNash@fhfc.org. This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (#EA-0060-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@franciscanchildrens.org.
114 parents, including 111 primary caregivers for their children, participated in Survey 5. 97% of participating parents were mothers and 79% were part of a two-parent household. 45% of parents did not work outside the home, 32% work full time, and 24% work part time.

Parents had an average of 2.1 children living in their homes (range: 0 to 6), including 1.2 children with a complex medical condition. 33% of the children required a tracheostomy or ventilator or were approved for block nursing. The children’s ages ranged from 2 to 26 (average: 12).

24% OF THE PARTICIPANTS (27 OF 112) HAD A CARE COORDINATOR

76% OF THE PARTICIPANTS (64 OF 84) WITHOUT A CARE COORDINATOR WOULD LIKE TO HAVE ONE

Of those 27 patients with a care coordinator:
- 52% (14 of 27) required a tracheostomy or ventilator or were approved for block nursing.
- Required an average of 7.2 specialists (range: 0-14).
- 63% (17 of 27) were in a two-parent household.
- 54% (14 of 26) had only one care coordinator. Others had up to 5 care coordinators.

Of those 85 patients without a care coordinator:
- 27% (23 of 85) required a tracheostomy or ventilator or were approved for block nursing.
- Required an average of 5.9 specialists (range: 0-14).
- 83% (70 of 84) were in a two-person household.

CARE COORDINATION SERVICES

Parents needed to communicate with their care coordinator an average of 2.6 times/month (range: 1-10, 26 responses) but they were only able to successfully communicate with them 1.6 times/month (range: 0-5, 25 responses).

60% of those with a care coordinator (15 of 25) were not satisfied.

Parents’ suggestions for improving care coordination included:
- Help with access to community programs such as Team IMPACT or others.
- Help looking at the big picture.
- Having one go-to person who helps with everything that comes up. Right now for the most part everyone just gets updates from me.
- Having them facilitate communication between providers and with providers on our behalf. Mostly, they are good for advice on how I should handle it, but they have little power to actually be able to facilitate anything.
- Provide follow through directly with all agencies, DME providers and medical specialists and follow-up when issues arise until they are resolved.

Parents, both those who have care coordination help and those who would like to have care coordination help, wanted care coordinators to help them access health services (80%, 91 of 114), access social support (77%, 88 of 114), and regularly contact the family (75%, 85 of 114), among many other needs. However, parents who currently have care coordination help reported receiving lower levels of all services, including the most commonly reported services: access to health services (44%, 12 of 27), tracking health information (44%, 12 of 27), and monitoring needs and goals (41%, 11 of 27). 15% of parents with care coordinators (4 of 27) were not receiving any services from their care coordinators.
Parents who have or would like to have care coordination help most frequently wanted that coordination to be provided by their child’s PCP office (42%, 38 of 90) and least frequently wanted that coordination to be provided by the child’s insurance company (21%, 19 of 90).

However, the frequency of actual care coordination providers was reversed: care coordination was provided by children’s PCP offices for 22% of parents (6 of 27) while it was provided by the child’s insurance companies for 33% of parents (9 of 27).

Parents who had or would like to have care coordination help most frequently wanted coordination to be paid for by insurance companies (79%, 72 of 91), followed by the state (43%, 39 of 91). Those were the two most frequent coordination payers (50%, 10 of 20, and 60%, 12 of 20, respectively) among those parents who knew who paid for these services.
Parents preferred their child’s care coordinators to be social workers (60%, 53 of 89), nurses (52%, 46 of 89) or nurse practitioners (47%, 42 of 89).

<table>
<thead>
<tr>
<th>Role</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>60%</td>
</tr>
<tr>
<td>Nurse</td>
<td>52%</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>47%</td>
</tr>
<tr>
<td>Physicians assistant</td>
<td>31%</td>
</tr>
<tr>
<td>Other non-medical staff</td>
<td>28%</td>
</tr>
<tr>
<td>Physician</td>
<td>20%</td>
</tr>
<tr>
<td>No opinion</td>
<td>4%</td>
</tr>
</tbody>
</table>

Half of parents with a preference (53%, 31 of 59) desired a care coordinator who was not their child’s care provider, and most care coordinators in the survey (78%, 21 of 27) were not the child’s care providers.

<table>
<thead>
<tr>
<th>Desired coordinator not be child's care provider</th>
<th>53%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Actual coordinator was not child's care provider</td>
<td>78%</td>
</tr>
</tbody>
</table>

Parents gave the following reasons why they want someone other than their child’s care provider to provide their child’s care coordination services:

- Greater chance for non-bias approach.
- They may offer a different outlook about my child and what services they need.
- I need help that is non-medical.
- I don’t think the care providers have the time to do an adequate job. I do think they need to be very involved in giving information and support to the person doing the job.
- I’d prefer someone who can see things from all angles - give a fresh perspective - and not be hyper-focused on their own specialties.
- Independence. Broader knowledge base. However they need access to all staff - high enough authority not to be ignored inside & outside of specific healthcare orgs. ie: ‘director’ not ‘coordinator’
- My child’s care providers need to concentrate on providing care, not organizing it. The distraction of administrational work will diminish their competency as care providers.
- I want them to have knowledge of a wide variety of services and providers.
- The PCP is not as easily accessible to communicate with and isn’t aware of all the resources.
- Care coordinators who are not also care providers have more time to spend with family.

**MEDICAL HOMES**

A "medical home" is a medical primary care practice with care coordination experts who know how to work with other parts of the health care system, including insurance. Of the 96 survey participants who knew whether their provider was a medical home, 17% of the patients (12 of 96) received their care through a medical home and 75% of the medical home participants (9 of 12) were satisfied.

Among the 57 participants whose child’s care was not provided through a medical home but whose parents had an opinion, most (89%, 51 of 57) wanted their child to receive care through a medical home, particularly if they didn’t have to change medical providers.

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, and would change providers</td>
<td>28%</td>
</tr>
<tr>
<td>Yes, if current provider changed</td>
<td>61%</td>
</tr>
<tr>
<td>No</td>
<td>11%</td>
</tr>
</tbody>
</table>
CARE TEAMS

A "care team" is a group of medical professionals from different disciplines (nursing, respiratory, PT or pharmacy, etc.) who work together to help patients.

- 13% of parents (14 of 112) reported having a care team visit their home and 77% of these parents (10 of 13) were satisfied with the services provided by the care team.
- 72% of parents without a care team would like one (69 of 96).

Parents reported the following benefits to having a care team:

- Delegating tedious emails, phone calls and tasks to them.
- With the care team nurse, we get to have ongoing relationship regarding my child's changing medical needs, help navigating the nuances, and discussion about goals and how to get there.
- I get to vent. Also, the NP cuts through the red tape to get us appointments.
- I have to let them in my house otherwise they'll call CPS.
- Saves time from going into the clinic for a visit.
- They get to see my child’s healthcare issues in real life at home. Seeing the child in their natural environment helps the care team better understands my child’s comprehensive needs.
- They tell me about programs and vouchers that we qualify for.

Parents reported the following drawbacks to having a care team:

- It means that there are a lot of people coming to our home each week.
- We have difficultly filling sick calls.
- They don’t give us much advance notice for visits.
- They usually come at a busy time of the day for us and they have to see the child as well. If my child’s bus is late or we have an activity, we have to wait until they come.
- They don’t allot enough time to each visit due to lack of funding given to the program and high demands of the case they are providing care for.
- The department seems very overwhelmed.
- We have to pay for them out of a limited budget so they can only come 1-2x a month. And only a nurse comes.

81% of parents (91 of 112) wanted services from a care coordinator or from a care coordinator and a care team.

<table>
<thead>
<tr>
<th>Service Provided</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care coordinator</td>
<td>42%</td>
</tr>
<tr>
<td>Care coordinator and care team</td>
<td>39%</td>
</tr>
<tr>
<td>Care team</td>
<td>11%</td>
</tr>
<tr>
<td>Neither</td>
<td>8%</td>
</tr>
</tbody>
</table>

HOME VISIT FOR DME SUPPORT

For parents of children who are ventilator or trach dependent, 56% of these parents (37 of 66) would like a licensed professional (example: a respiratory therapist) to visit their home to review their child’s equipment and procedures with them.

Among those wanting a visit, parents wanted the visits annually (38%, 14 of 37) or biannually (32%, 12 of 37).
95% of parents (105 of 111) agreed that medical providers (doctors, nurses, physicians’ assistants, etc.) should receive formal training in coordinating care and services for patients with complex medical needs.

Parents expected the following benefits from this training:

- **Improved awareness:**
  - Of the child as a whole person, not a set of symptoms.
  - Of the extreme complexity and nuances of a complex chronic patient.
  - Of the guilt, burden, frustrations, and everyday life that come with each change in plans, disagreement between care teams, hospitalizations, and new orders.
  - Of family centered care.
  - Of care coordination and its benefits to the patient and their family.
  - Of the services we need and more willingness and ability to help us get these services.
  - Of how to navigate the system for us so parents aren’t left alone trying to figure it out.

- **Improved referral practices:**
  - Ability to provide/recommend care rather than send us to another doctor.
  - Better understanding of other services to recommend.
  - Improved ability of specialists to see the entire child, not just their area of specialty.
  - Read referral/specialist notes before the visit to be aware of other providers’ recommendations, medications and opinions.
  - Consult with other providers prior to the visit to decide together on best next steps.

- **Improved communication skills and practices:**
  - A willingness to see me as the expert of my child (I see them as the expert in their field) so we can better collaborate.
  - Better communication between providers.
  - Improved accuracy, timeliness and consistency of communication with patients and parents.
  - Inclusion of patients and parents in the discussions between providers.
  - Understand the challenges parents face when trying to communicate within the system.

- **Care Coordination:**
  - Every person involved in my child’s care should be regularly updated on what is going on with him.
  - Help everyone get on a level playing field, not just families with a ‘good’ doctor or connections.

- **Broader Knowledge:**
  - An understanding of the needs of the child with complex needs medically, socially, spiritually, educationally, as well as how this impacts the siblings, parents, grandparents, friends, community.
  - Cultural competence, integration of care.
  - Learn the roles other play (e.g. orthoptist, physical therapist, etc.)
  - Of how to work better with insurance companies and other hospitals and clinics;
  - Of how their orders can or cannot be realistically enacted outside the clinic.
  - A stronger sense of obligation to remain up-to-date with the patient's larger medical care plan, home life, and overall care.
  - Of the broken system that does not allow us to receive medical care and prescribed equipment in a timely and safe way.
  - Of the complex layers parents navigate and work to improve them along with the parents.
  - Reminder that home care may look very different from hospital care.
MEDICAL PROVIDERS: IMPROVING COMMUNICATION

Parents’ key recommendations for improving communication was linking records across networks (68%, 75 of 111), having medical passports maintained by the families (59%, 66 of 111) or scheduling teleconferences for all specialists (56%, 62 of 111), among other solutions.

Parents' key recommendations for improving communication:
- Electronic health records linked across networks: 68%
- Medical passport (record across professionals maintained by the family): 59%
- Teleconferences for all specialists on a case: 56%
- Communication training in medical/nursing school: 47%
- An awareness campaign targeted to professionals: 28%
- Electronic health records that cannot be submitted until complete: 23%

SHARING A CHILD’S HEALTH INFORMATION

86% of parents (96 of 111) would like to control who has access to their child’s health information.

97% of parents (108 of 111) would like access to their child’s medical records.

HOME CARE NURSING

36% of patients (40 of 112) were approved for home care nursing while 22% of the remaining parents (16 of 72) thought their children needed home care nursing.

Most parents would agree to be paid to fill their child’s home nursing care hours themselves, either the unfilled hours (33%, 13 of 38) or both the filled and unfilled hours (58%, 23 of 38).

Two-thirds of parents whose children were approved for home care nursing (26 of 39) reported being unable to completely fill their approved hours. On average, parents were short 28 hours (range: 4-134).

Regardless of their success in filling hours, parents reported working with an average of 1.4 agencies to try to fill home care nursing hours.

In some cases, of 19 parents reporting, unfilled nursing hours resulted in unplanned doctor visits (4 reports of 1-4 visits), ER visits (3 reports of 1-2 visits), hospital admissions (3 reports of 1-2 admissions), or other significant healthcare events (4 reports of 1-4 events).

Parents unable to fill nursing hours reported that during unfilled shifts, they provided free care (73%, 19 of 26), an untrained friend or relative provided free care (19%, 5 of 26), they pay an untrained worker to provide care (8%, 2 of 26), or their child goes without care (12%, 3 of 26). No one reported receiving free or paid trained care for his or her child.

Parents reported the following reasons for being unable to fill all of their home care nursing hours:

- Availability of qualified nurses
- Agency refuses to fill hours claiming not enough qualified nurses
- Lack of availability of nurses with both behavioral and medical training
- Low pay, no benefits
- Nurses do not have ventilator training
- Nurses don’t want to work in the home they say it’s boring
- Respite & school nursing only
- Budget issues at the county level
87% of parents whose children receive home care nursing (34 of 39) reported having one or more problems with home care nurses.

76% of parents with children with tracheotomies or who were ventilator-dependent (13 of 17) reported having a home care nurse show up for a shift who was not tracheotomy- or ventilator-trained. Parents very frequently trained the nurse themselves (92%, 12 of 13) and often took the place of the nurse until a trained nurse was found (46%, 6 of 13). Training by the parent took an average of 8 nursing shifts to complete.

Among 38 parents reporting, undertrained nurses resulted in unplanned doctor visits (7 reports of 1-2 visits), ER visits (3 reports of 1 visit), hospital admissions (3 reports of 1 admission), or other significant healthcare events (7 reports of 1-3 events).

Other problems that parents reported with home care nurses included:

- Abuse and neglect, threatening behavior
- Lack of available and qualified staff
- Frequent staff turnover
- Nurses sleeping on the job
- Nurses not speaking English as primary language
- Nursing using drugs/alcohol on the job
- Inadequate training of new nurses
- Nurses who argue with our family’s medical preferences or our care plan as created by doctors
- Personality conflicts with family and/or patient
- Scheduling issues, not showing up or taking time off without informing us
- Lack of patient care experience
- Some nurses are bored with home care nursing
- They are not properly trained on how to remain professional in someone’s home

Parents preferred to report problems with their home care nurses to the home nursing agencies or to the state nurse licensing board equally (both 62%, 24 of 39) but 85% of parents (33 of 39) actually reported problems to home nursing agencies while 31% of parents (12 of 39) reported problems to the state nurse licensing board.
56% of parents (18 of 32) agreed that reporting problems to the home nursing agency was effective. Parents who found reporting to the home nursing agency ineffective described the following reasons:

- Agency often blames the parent.
- It might solve that specific issue but there will always be issues and the next nurse might be worse.
- The nurse is rotated to another case.
- If you complain about your nurses, the agency does not make an effort to fill your hours.
- There is no consequence or accountability by the nurses because they know we are desperate for help and if we fire them, we have no other nursing help.
- Training has not improved.
- We have experienced very little effective correction of issues through nursing agencies.

67% of parents (6 of 9) agreed that reporting problems to the state nurse licensing board was effective. Parents who found reporting to the state nurse licensing board ineffective cited the following reasons:

- Our nurse fell asleep on several occasions while caring for our son overnight including when he was released from the hospital after a near deadly infection and she slept through alarms and while training a new nurse who had no idea what to do. We reported it to the agency who then reported her to the state and the nurse does not have a blemish on her record and is still caring for patients. The nurse being oriented testified as well as the agency because it was that serious and nothing happened to her.
- I have never heard back from any state agency regarding the nursing complaints I have made.
- It is very difficult for grievances to be filed, heard, proven, and it is a fact that major issues occur with nurses even after reporting to the nursing board. They just leave one agency and move onto another, or go independent as a MassHealth nursing provider. Families see nurses that should have been removed from home healthcare resurface on different family cases all the time. Good thing we talk to each other in order to protect our children and families from nurses that should no longer be allowed to practice.

Parent suggestions for reporting problem reports included:

- There should be a person at the state level who takes all complaints of a serious nature and a list of nurses who have had infractions against them but not on their record so other families have an idea about that nurse and can make their own decision whether to hire or not. There has to be a database or someone specifically in charge of this information but not used for petty information. If you can get information on businesses you should also be able to get it on nurses caring for your loved ones.
- Issues must be tracked if they nurse has ever put a child’s health at risk, even if it does not meet the current state board ‘fire-able’ checklist.
- Report through the insurance company or a third-party payer, in this case MassHealth
- Report to a third party that does not rely on the nurse for revenue like a nursing agency does
- Track grievances with someone other than the current state licensing board – they make it too hard to prosecute nursing grievances.

**EVALUATING HOME NURSING CARE**

Parents preferred home nursing care evaluations to be the responsibility of clinical case management teams (58%, 23 of 40) or an independent agency (55%, 22 of 40) rather than the nursing agency (40%, 16 of 40) or a government agency (28%, 11 of 40).
90% of parents (35 of 39) were willing to regularly fill out a satisfaction survey for each nurse working in their home. Most parents (77%, 27 of 35) preferred the nursing agency assume responsibility for addressing the results of such a satisfaction survey.

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing agency</td>
<td>77%</td>
</tr>
<tr>
<td>State agency</td>
<td>40%</td>
</tr>
<tr>
<td>Insurance provider</td>
<td>20%</td>
</tr>
</tbody>
</table>

95% of parents (37 of 39) would look at satisfaction survey results before accepting a home care nurse assigned to them either to determine whether they should seek a replacement nurse (64%, 25 of 39) or to prepare for that nurse’s weak points (33%, 12 of 39).

<table>
<thead>
<tr>
<th>Option</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, and may seek replacement</td>
<td>64%</td>
</tr>
<tr>
<td>Yes, to prepare</td>
<td>33%</td>
</tr>
<tr>
<td>No</td>
<td>5%</td>
</tr>
</tbody>
</table>

**MEDICAL INSURANCE**

All parents (out of 112) reported having health insurance for their children. Most parents (63%, 71 of 112) reported a combination of private and government insurance.

Most parents (77%, 84 of 109) wanted their insurance company to provide a care coordinator or case manager to help them understand their child's health coverage, but that service was available to 54% of parents (59 of 109). Among those with these services, some found them easy to access (32%, 19 of 59) and few found them easy to understand (19%, 11 of 59) and/or accurate (22%, 13 of 59).

<table>
<thead>
<tr>
<th>Desired</th>
<th>Care Coordinator or Case Manager</th>
<th>Available</th>
<th>77%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy to access</td>
<td>Among those with access to a care coordinator or case manager:</td>
<td>32%</td>
<td></td>
</tr>
<tr>
<td>Easy to understand</td>
<td>19%</td>
<td>77%</td>
<td></td>
</tr>
</tbody>
</table>
Half of parents (50%, 55 of 109) wanted their insurance company to provide a website to help them understand their child's health coverage, and websites were available to 92% of parents (100 of 109). Among those with website access, most (68%, 68 of 100) found them easy to access while few found them easy to understand (20%, 20 of 100) and/or accurate (20%, 20 of 100).

Few parents (31%, 34 of 109) wanted their insurance company to provide a customer service phone help line to help them understand their child's health coverage, and help lines were available to 94% of parents (102 of 109). Among those with help line access, many (58%, 59 of 102) found them easy to access while few found them easy to understand (17%, 17 of 102) and/or accurate (18%, 18 of 102).

Few parents (23%, 25 of 109) wanted their insurance company to provide written materials to help them understand their child's health coverage, and written materials were available to 64% of parents (70 of 109). Among those with written material access, many (53%, 37 of 70) found them easy to access while some found them easy to understand (31%, 22 of 70) and/or accurate (26%, 18 of 70).
More parents got information on prior authorization processes through customer service phone help lines than from other sources.

- Among those who received a denial, 59% of parents (30 of 51) had at least one denial due to clerical error, averaging 1.9 denials due to clerical error (range: 0 to 15).
- Among those who received a denial, 17% of parents (9 of 54) had a denial that required a hearing, averaging .3 denials requiring a hearing (range: 0 to 3).
  - Hearings took 10 to 180 days (average: 68 days, 8 reporting).
  - Parents whose denial required a hearing reported that an average of 16.3 days is an acceptable wait for a hearing to occur (range: 0 to 30, 8 reporting).
  - Hearings affected the health of 5 out of the 9 children whose denial went to hearing.
    - He didn't have adequate PCA support
    - Had anaphylaxis while waiting for approval of a medication
    - Couldn't pick up a prescribed medication on time
    - Did not get PT and was admitted to hospital twice
    - Had no medications or therapy

The average parent received 2.4 denials in the past 12 months (range: 0 to 20, 101 reporting).
INSURANCE SATISFACTION SURVEYS

77% of parents (81 of 105) would be willing to fill out a satisfaction survey regarding each interaction with their insurance company.

If insurance interaction satisfaction survey results were lower than preferred, half of parents (51%, 54 of 106) would ask their insurance company about improvement plans. Some parents (30%, 32 of 106) would take no action.

Parents opinions varied regarding who they thought should assume responsibility for addressing the results of a satisfaction survey with group/agency endorsement ranging from 15% (clinical case management team, 16 of 104) to 31% (insurance provider, 32 of 104).

OTHER INSURANCE-RELATED NEEDS

96% of parents (101 of 105) would like their insurance company to alert them when a prior authorization (PA) is close to expiring.

66% of parents (69 of 105) would want to know whether anyone from their child's provider's office has attended policies and procedures training sessions and updates for medical providers and their office staff.

91% of parents (96 of 105) thought it would be helpful if their insurance provider offered training sessions on insurance-related issues for parents of children with chronic, complex medical needs.
**OBTAINING MEDICAL SUPPLIES**

67% of parents (70 of 104) have worked with a DME company to get their child’s medical supplies.

- Of those parents, 78% (52 of 67) reported that if their medical supply order is not correct (either wrong items or wrong amounts), the DME Company fixes the problem in a timely manner once notified.

Those who did not agree used the following strategies to address incorrect medical supply orders:

- Call and email the DME and keep calling until they get it right, call all parties involved
- Escalate the issue to a department manager
- Change DME provider
- Get the care team and insurance company to intervene with DME (this can delay next order because of how long it takes to resolve the issue).
- If they send me the wrong items or too many, they generally never retrieve them. Not sure who gets billed.
- Live with the problem

Parents suggested the following improvements:

- Provide each family with a real contact person
- Train DME employees on how to accurately take orders and implement better warehouse systems to ensure that sent orders are accurate.
- customer driven not medicaid driven
- Confirm orders online
- Standardized forms feedback on claim status
- Systems have to be developed from the time a company receives a Prior authorization request to the time a piece of equipment is received. They need to be held accountable by insurance companies and MassHealth to track every step of the process in a timely way and to communicate this process to patients.
- Use a multiple access point portal online to connect various providers & DME with family/individual. Still providing call-in assistance (*should trademark that now)

24% of parents (16 of 67) reported that if their medical supply order was not correct (either wrong items or wrong amounts), there was someone other than the DME company that they could report it to including:

- Care coordinator or case manager
- High acuity
- Hospital
- Insurance company
- Gastro team
- Pediatricians office
- Social Worker

Compared to other options, more parents agreed that they should be able to report incorrect DME orders to the DME company (37%, 25 of 67).
65% of parents (45 of 69) would be willing to fill out a satisfaction survey each time they received their child's medical supply order. Compared to other options, more parents agreed that the DME company should assume responsibility for addressing the results of the satisfaction survey (40%, 18 of 45).

Most parents (67%, 47 of 70) agreed that having access to DME satisfaction survey results would impact the DME company they select.

90% of parents (61 of 68) would support a system where the insurer reimburses the DME company ONLY after delivery of a correct order. Anticipated results of such a system included more correct first deliveries (76% agreement, 53 of 70), more responsiveness to complaints (67% agreement, 47 of 70), among others.

Other parent reactions to the above idea to reimburse DME only after a correct order is received:

- Concern that it will result in a delay in delivery.
- DME would be more alert to mistakes. constant ordering problems could result in the insurance dropping them as a provider.
- I strongly believe that this is not the solution - families would have to fight even harder to get anything from a DME provider.
- It could limit the suppliers/companies a DME could offer based on billing systems on all ends.
- This process will increase more workload to caregiver and DME company, increase service cost and make the process less efficient.
- We do not live in a perfect world.

81% of parents (83 of 102) would use a mobile app to re-order their child’s medical supplies.
Among families who have needed large medical equipment moved, most parents (73%, 22 of 30) move larger equipment like hospital beds to a new home themselves. When a mover is used, parents pay for it more often (23%, 7 of 30) than the DME provider (10%, 3 of 30) or insurance company (3%, 1 of 30).

Among parents who have had the need, DME arranges for equipment repair (37%, 19 of 51) or replaces damaged equipment (22%, 11 of 51). Often, parents repair or arrange for repair themselves (45%, 23 of 51).

Among these same parents, repairs are most often paid for by insurance companies (65%, 33 of 51) or DME companies (29%, 15 of 51).

On average, repairs took 33 days (range: 0 to 180, 45 reported).

27% of parents whose children (older than 3 years of age) needed diapers/briefs (14 of 51) bought their children’s diapers/briefs out of pocket for the following reasons:

- Can’t get preferred brand through insurance
- Can’t get it covered by private insurance
- DME provider cannot find correct code for billing
- Have not found a DME to provide
- Unaware that the insurance company would cover them
- The diapers provided by insurance are very low quality resulting in leaks and more laundry

31% of parents whose older children needed diapers/briefs (15 of 49) reported that their child experienced health issues caused by poor quality of insurance-provided diapers/briefs:

- Diaper rash, skin breakdown
- Urine and stool leak out
- Diaper rashes, abrasions and pressure sores due to shearing/poor fit
- My daughter has extremely sensitive skin and gets rashes and blisters from poor quality fitting diapers
- Skin irritation, scratches from tape
- Ostomy bag falling off, medical tape and patches getting soaked and falling off
### DME Company Size

49% of parents who had worked with a DME company (33 of 68) had worked with both a smaller, local DME company and a larger, regional/national DME company. Within those parents, 55% (18 of 33) would prefer a smaller, local DME company.

Parents described the following benefits of working with a smaller, local DME company:
- Better customer relationship including personal care and service
- Better and faster response times
- Better delivery with more flexibility in delivery times, and faster responses to errors.
- If we need something quickly we can pick it up.
- MassHealth works with them.
- They know your needs well. Work with the same person every month. You’re not a number. Solves problems quickly, Get equipment faster, Fixes issues faster. Very personalized. All I need to do each month is send an E-mail when we need our supplies and done it comes in two days. When I do call I can understand clearly the person on the phone with me. Speaks clearly. Returns calls & E-mails quickly
- Trained RTs, more responsive
- You can get what you need quickly. We had really bad experiences with national companies.

12% of parents who had worked with both sizes of DME companies (4 of 33) preferred larger, regional/national DME companies.

Parents described the following benefits of working with a larger, national company:
- Consistency
- Greater access to variety of products
- More specialized knowledge
- Hopefully won’t go out of business
- They ship everywhere
- More access to customer service, more access to back-ordered products.
- More efficient
- They seem to want to help more
- Better ways to confirm orders
- We are able to get things quickly, albeit this is a hospital based DME
- You can have items delivered when you’re on vacation out of state.