

Comprehensive Long-term Follow-up for Colorado and Wyoming Family Engagement Projects: Summary of Qualitative Data

Background

Understanding whether the long-term follow-up (LTFU) system is working for families is critical to measuring the long-term success of newborn screening (NBS) and to understanding why some families are lost to follow-up.

Methods

Parents and caregivers of children diagnosed with a condition as a result of a positive/abnormal NBS were recruited from six pediatric specialty care clinics. Data was gathered from caregivers via six focus groups and open-ended responses on a survey. Caregiver participants represented a wide range of NBS-related conditions and children's ages.

SURVEY

March – August 2023



- Most questions were quantitative and asked about families' experiences with LTFU care; there were two open-ended questions.
- Responses to the open-ended question "What, if anything, would improve the care you want and need for your child?" were included in the analysis.

33
**Family Caregiver
Respondents**

FOCUS GROUPS

May – July 2023



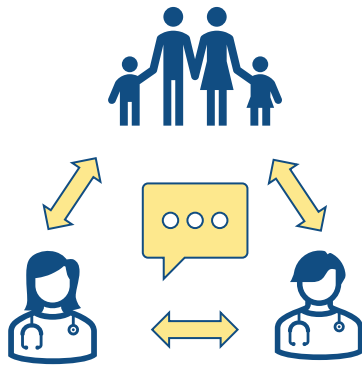
- Six semi-structured focus groups were conducted online.
- Participants were given \$150 gift cards for their time.
- Caregivers were asked for their perspective on good LTFU care, barriers and facilitators to LTFU, and goals they have for their children.

24
**Family Caregiver
Participants**

Results

Key Factors That Comprise or Influence Long-term Follow-up Care

Communication and Relationships with Providers



- Bidirectional, respectful, flexible, and timely communication should take place between the family and the specialty provider, the specialty provider and other care providers (e.g., primary care, emergency care, hospitalists, etc.), and the family and other care providers.
- A variety of communication modes are appreciated by caregivers, including patient portals, email, phone, and in-person meetings.
- Providers on the child’s care team should communicate directly with each other rather than relying on the family to relay information.
- Caregivers want to be listened to when they voice specific preferences for their child’s care; they are the experts when it comes to their child.
- Communication breakdowns between the family and providers can hinder families’ access to and maintenance of LTFU care.
- The relationships between families and their children’s providers are a key factor in quality LTFU care. Positive family-provider relationships contribute to family empowerment in LTFU decision making, giving caregivers the confidence to push back on providers when they feel it is necessary.

Quotes

“Quality care for me has been the response time to questions, because we have to feed them every day and sometimes, especially in the beginning, in your first year of PKU, the worry that goes along with what, if what you're doing is going to be damaging, I would say quick response time is really important.”
- Focus group participant

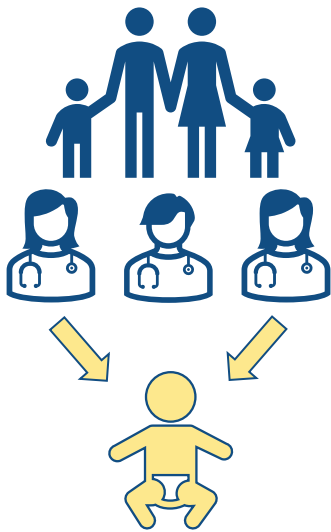
“One time we went to the emergency room, [child] was really sick, and I told the nurse this arm is really the best one to do [the blood draw]. [Nurse] didn't listen to me, and she did it on the right and the arm was really swollen ... Now, [child] gets really anxious about just going to the hospital because of drawing her blood.” - Focus group participant

“The three different groups [family, specialist, and pharmacy] - your triangle has to be working well and sometimes it doesn't all fire on the same cylinders at the same time.” - Focus group participant

Results (cont.)

Key Factors That Comprise or Influence Long-term Follow-up Care

Care Team Roles and Factors



- Caregivers play a central role in accessing and maintaining LTFU for their child. They are an integral member of their child’s care team.
- Caregiver burnout, denial, fear, feeling overwhelmed, or previous negative experiences can be barriers to families staying engaged in LTFU care.
- Connection to other families living with a similar condition and psychosocial supports can help families in accessing and maintaining LTFU care.
- Caregivers’ responsibilities include advocating for their child, staying on top of appointments, communicating with the care team, building relationships with their child’s providers, and educating non-specialty providers on their child’s condition and needs.
- Successful LTFU care involves a team of providers who treat the whole child.
- A role often missing on the LTFU team is that of a care coordinator; this is something caregivers want and need to help manage their child’s care across the team of providers and the high volume of appointments.
- Lack of knowledge among non-specialty providers makes it difficult to get the care families need for their child.

Quotes

“I’ll just ask to get a blood draw done, even if [provider] tells me, ‘No, that’s not a symptom.’ And there was one time that [provider] was off, and [child] did need a dosage change, but other than that I try to listen. I try not to be that overbearing parent, but I am also the voice for my daughter. So, I’m like, ‘No, let’s just go get [child] checked.’”
- Focus group participant

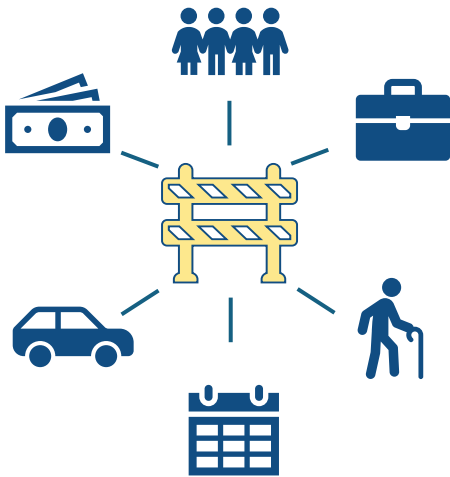
“It is a whole team of people that we see ... they do treat the whole person. And it’s like right now ... we don’t need a psychologist so much because she’s a little kid ... I understand why that’s such an important part of the team ... They have so many people in place to manage every aspect of the disease, emotional, physical. That’s huge.”
- Focus group participant

“They [non-specialty providers] have no idea what [the condition] is, so it’s like you have to explain it to them.”
- Focus group participant

Results (cont.)

Key Factors That Comprise or Influence Long-term Follow-up Care

Care Access and Utilization Factors



- Lack of insurance, poor insurance coverage, complex enrollment processes, and difficulties obtaining treatment authorization make it difficult for families to get the LTFU care they want and need.
- Public insurance programs, such as Medicaid, Children’s Health Insurance Program (CHIP), and TriCare are very beneficial to families’ LTFU care.
- Caregivers would like access to insurance specialists who can help navigate complex insurance issues.
- Difficulty getting to their child’s medical visits – due to geographic distance, weather, issues with transportation, or no internet access (for telemedicine visits) - is a barrier to accessing and maintaining LTFU.
- Families’ obligations such as caring for other children or elderly parents, work, and school can make it difficult to access and stay engaged in LTFU.
- Scheduling issues, including not being able to reach the right scheduler, not being able to bulk schedule appointments on the same day, difficulties rescheduling appointments, and long wait times for appointments make it difficult for families to access LTFU.

Quotes

“... to have maybe an insurance specialist or something that could navigate all the different insurances and help families get on Medicaid ... and [the] clinic, while they try and offer suggestions, I think they’re so busy dealing with just the medical aspect of it. It might be nice to just have somebody that can help with the insurance and financial.”
- Focus group participant

“Yeah, it’s really hard. Actually, my husband lost his job because ... of the whole hospital stay ... My son has the medical condition, has siblings, so [caregivers] have to share the duties.”
- Focus group participant

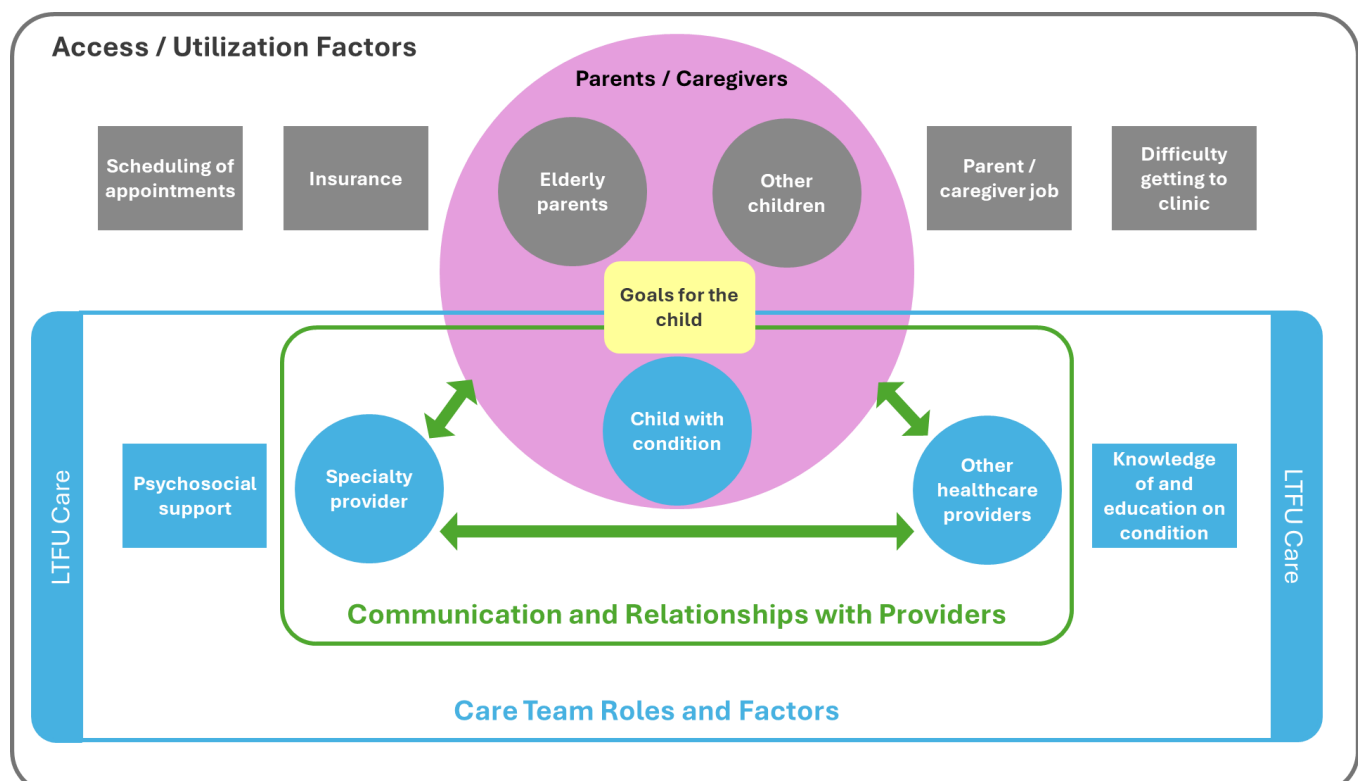
“Every year the reauthorization process for her medication is exhausting and cumbersome. There is lots of room for process improvement - on the insurance side of this.”
- Survey respondent

Results (cont.)

A Model of Long-term Follow-up Access and Engagement

A Model of LTFU Access and Engagement from the Caregivers' Perspective

- A model was developed to depict the interplay of the themes identified in accessing and engaging in LTFU care from the caregiver's perspective.
- In this model:
 - The caregivers play a vital role, with their family at the core of LTFU.
 - Within the family unit are the parents'/caregivers' goals for their children which may guide the family and the rest of the care team in caring for the child as a whole person who is not defined solely by their disease.
 - The family and provider relationship, which is built through communication, is also at the core of the model.
 - Communication and relationships between the family and providers, along with supportive factors (i.e., psychosocial support for the family and knowledge and education for the family and providers), comprise LTFU care in the model.
 - LTFU care operates inside an environment that is impacted by access and utilization facilitators and barriers (i.e., scheduling, insurance, elderly parents, other children, work, and transportation to the clinic).



Results (cont.)

Caregivers' Goals for Their Children

Caregivers' Health Related Goals for Their Children



- Child will be able to care for self in the future.
 - They will have more autonomy in their care.
 - They will be able to self advocate.
 - They will be able to access and utilize resources to help with their condition.
 - Their medications will be reduced.
 - They will not have to deal with insurance issues.
- Child won't be hindered by diagnosis.
 - Their condition will be eradicated or cured.
 - They will live a long life.
 - They will meet developmental goals.

Caregivers' Non-health Related Goals for Their Children



- Child will be able to define self outside of disease.
- Child will be able to educate others on their disease.
- Child will be able to communicate using a tablet.
- Child will be able to do typical kid things.
 - They will learn to drive.
 - They will make friends.
 - They will be able to participate in sports.
 - They will be able to attend sleepovers.
- Child will feel included in life.
- Child will have good relationships with people outside the immediate family.
- They will be a nice person.
- They will live a normal life.
- They will become more independent.

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For More Information

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