



# Discovery Phase Report: **NICU Parent Engagement**

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Prepared for DEFINE Colorado by:  
**Causeworthy**  
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# Executive Summary

## Executive Summary

**Hello Home** is a digital platform designed to support families—especially mothers—through the complex transition from the neonatal intensive care unit (NICU) to home. This concept was developed through a multi-phase research and design process led by DEFINE Colorado in partnership with Causeworthy. The goal was to identify scalable, evidence-informed solutions to address a well-documented and persistent gap in care following NICU discharge.

## Background and Purpose

11%



of infants born in Colorado are admitted to the NICU, with Black mothers significantly more likely to experience preterm birth and its associated complications.

Each year, approximately 11% of infants born in Colorado are admitted to the NICU, with Black mothers significantly more likely to experience preterm birth and its associated complications. While NICUs provide high-touch, team-based care, families report feeling isolated and underprepared when this support ends at discharge. Quantitative data from CDPHE and PRAMS, as well as qualitative insights from DEFINE's statewide research, underscore the widespread impact of this transition — particularly on maternal mental health, economic stability, and access to post-discharge resources.

**DEFINE Colorado** and **Causeworthy** (formerly 3 Story Design) conducted a comprehensive landscape analysis, parent and provider interviews, and statewide surveys to understand existing resources, family preferences, and gaps in support. The research focused on **four core questions**:

- What digital tools currently exist for NICU families?
- Which outreach campaigns and resources resonate most with parents?
- What mediums do NICU families prefer for receiving support?
- How does the data support the need for a centralized solution?

Findings revealed that while hospitals, nonprofits, and national organizations offer individual tools and educational content, there is no cohesive, statewide platform designed to meet the full spectrum of NICU families' needs. Providers are aware of the depth and range of needs but have limited resources and bandwidth to support. Parents shared that they often rely on fragmented or outdated resources, struggle with care coordination, and are overwhelmed by medical information at discharge. Many families, especially those from rural or linguistically diverse communities, are left to navigate complex systems with little or no support.

## The Solution: Hello Home

Hello Home is a centralized, web-based platform that offers emotional support, care navigation, and educational tools tailored to the needs of NICU families.

Key features include:

- Peer mentorship referrals and virtual support circles
- Digital discharge and follow-up checklists
- Customizable care trackers for feeding, medications, and developmental milestones
- Mental health screening tools and self-care guidance
- Culturally responsive content in multiple languages
- A vetted resource library including navigation tools to combat social determinants of health (SDOH) and trusted medical content (e.g., AAP, ACOG, March of Dimes)



# Executive Summary

Hello Home is being developed through a phased approach that includes research, prototype development, pilot testing across five Colorado hospitals, and eventual statewide expansion. The platform is designed for scalability and sustainability, with plans for national readiness.

## Impact and Opportunity

Hello Home fills a critical gap in systems and aligns with state and national efforts to improve perinatal health equity, maternal mental health, and family-centered care. It provides continuity, trusted information, and emotional support during a time of intense vulnerability.

The platform will measure impact through:

- Platform engagement and feature usage
- Maternal mental health outcomes and referral completion
- Infant health and developmental milestones
- Operational relief for care teams
- Equity of access across race, ethnicity, language, geography, and income

## Strategic Alignment and Next Steps

Hello Home intersects with several priority areas in public health and early childhood:

- Maternal-infant dyadic care
- Early intervention and school readiness
- Medicaid and policy alignment for digital care navigation
- Rural health and language access

The next phase of work will include:

- Formal platform evaluation in pilot sites
- AI-based personalization of content and referrals
- Integration with community-based services and pediatric systems
- Development of an adoption toolkit for Colorado and eventual national use
- Launch of an awareness campaign centered on parent stories and mental health advocacy

**Hello Home is not just a digital tool** — it is a transformational solution grounded in empathy, equity, and innovation. It offers a long-overdue extension of NICU care that empowers families, bridges clinical and community support, and ensures no family has to navigate the NICU-to-home journey alone.

# Overview of the Initiative

**DEFINE Colorado, a statewide quality improvement collaborative focused on equitable family engagement during NICU hospitalization, partnered with Causeworthy to better understand these needs and explore potential solutions.** Through this collaboration, we conducted a comprehensive analysis of existing NICU materials, campaigns, and platforms; surveyed and interviewed NICU parents and staff across four Colorado hospitals; and mapped current resource gaps against family and provider needs.

The purpose of the comparative research was to understand the landscape of NICU-related family support and identify evidence-based, scalable solutions that address post-discharge challenges. Specifically, the research sought to answer four key questions:

- What currently exists in the NICU space by medium, specifically for digital platforms?
- Are there outreach campaigns and resources that resonate with families?
- What mediums do NICU families prefer for receiving information and support?
- How does the data support the need for a new, centralized resource?

The Hello Home concept emerged from a clearly identified gap revealed through this research: families leaving the NICU face a dramatic shift from intensive, team-based medical care to a fragmented and often isolating post-discharge experience. Parents frequently describe the transition as overwhelming — moving from “many hands” to navigating their infant’s complex needs on their own. This period is marked not only by emotional distress and isolation but also by everyday challenges tied to job disruption, financial strain, and unmet social determinants of health (SDOH).

The findings from the research revealed that:

- Families consistently felt unprepared for the transition home.
- Many experienced emotional distress, a loss of community, and a lack of clarity in follow-up care.
- Hospital clinical team members lacked consistent tools to connect families to post-discharge resources.
- Parents expressed a strong desire for ongoing connection, real-time answers, and culturally inclusive, trusted materials.

Key themes emerging from research on the NICU discharge experience reflect the complex emotional and logistical challenges families face as they transition home. Parents described going through an emotional rollercoaster of leaving the structured, high-touch NICU environment and struggling with a sudden sense of isolation. Many expressed a lack of knowledge, often articulating, “you don’t know what you don’t know,” as they navigated unfamiliar medical needs without adequate guidance at home. The pressure to become an educator to family and friends further compounded their stress, as did the persistent feeling of being behind, whether in understanding their baby’s development, accessing support, or managing follow-up care. This was all made more difficult by the need to juggle competing responsibilities such as caring for other children, maintaining employment, and managing household finances. Families also noted how hard it was to ask for help, underscoring the need to normalize help-seeking and create systems that make support more accessible.

These insights confirmed that while isolated resources existed, there was no cohesive, digital solution tailored to the complexity of the NICU discharge experience, especially one that resonated with diverse families or met them in their preferred formats.

# Overview of the Initiative



Hello Home is conceptualized as a centralized, web-based resource designed to support families – especially mothers – during the vulnerable transition from NICU to home. Developed with an emphasis on equity, accessibility, and cultural responsiveness, the platform offers:

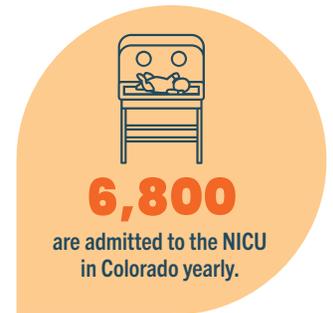
- Peer mentorship and virtual support circles to reduce isolation
- Customizable infant care trackers and discharge checklists to ease care coordination
- NICU-specific educational content tailored for parents and families, including resources for siblings and extended caregivers
- Mental health screenings, wellness check-ins, and referrals to counseling and community-based services
- A vetted, trusted resource library for both providers and families that includes:
  - › Family leave navigation tools
  - › SDOH resource directories
  - › Health literacy guides (e.g., glossaries, translated materials)
  - › Tools for educating family and friends
- Connection to peer supports, such as discharge doulas or respite care
- Integration with other aspects of the broader NICU discharge awareness campaign, including storytelling, social media engagement, and Lantern outreach

These findings directly shaped the conceptual design of Hello Home, ensuring it is both evidence-informed and grounded in the lived realities of NICU families. By aligning platform features with the research findings, Hello Home aims to empower families, reduce isolation, and strengthen connections to care and community.

# The Problem

**Each year, approximately 11% of infants born in Colorado — more than 6,800 babies — are admitted to the NICU (CDPHE Vital Statistics Data, 2023).**

This rate climbs in certain rural counties, where NICU admission percentages are among the highest in the state. Preterm birth remains a key driver of NICU admission, with 10% of all Colorado infants born before 37 weeks gestation (CDPHE Vital Statistics Data, 2023). Babies born to Black mothers are overrepresented in both NICU admissions and preterm births, reflecting persistent racial disparities in maternal and infant health outcomes (CDPHE Vital Statistics Data, 2023).



Nearly one in six NICU or preterm births occur in families earning less than \$15,000 per year, with a disproportionate share covered by Medicaid (CDPHE Vital Statistics Data, 2023). More than half of these births are delivered via cesarean section — compounding the ability for mothers to recover postpartum (CDPHE Vital Statistics Data, 2023). Mothers of NICU babies are more likely to begin pregnancy with pre-existing conditions such as diabetes or hypertension and face higher risks of complications including gestational hypertension and eclampsia (PRAMS data). They are also more likely to report smoking during pregnancy and to have received no prenatal care, further compounding postpartum risks (CDPHE Vital Statistics Data, 2023).

Postpartum mental health risks are elevated for mothers whose babies are admitted to the NICU: PRAMS data indicate that mothers of NICU babies are more likely to report depressive symptoms and hopelessness (PRAMS, 2020–2022). DEFINE cohort data show these concerns intensify post-discharge, with 19% of parents reporting their mental health was never or rarely addressed (DEFINE Cohort Survey), and more than one in five wishing they had received mental health support after going home (DEFINE Cohort Survey).

Families describe this transition as emotionally overwhelming — shifting from “many hands” in the NICU to managing complex care alone. Stressors include isolation, lack of information, disrupted employment, financial strain, and limited access to follow-up care. Nearly half of families in the DEFINE cohort traveled over 30 minutes to reach the NICU, with transportation, food, and medical bills noted as top concerns (DEFINE Cohort Survey). While 90% reported that NICU staff often checked in on them, fewer felt connected to lasting mental health resources (DEFINE Cohort Survey).

Despite these overlapping and well-documented challenges, there is no centralized, state-specific, trauma-informed resource in Colorado designed to support NICU families after discharge. Current systems lack culturally responsive tools, consistent care navigation, or peer support to reduce isolation and build confidence. Without targeted interventions, these gaps undermine both maternal mental health and infant developmental outcomes. **Hello Home is designed to directly address these unmet needs by providing families with trusted resources, coordinated supports, and a digital infrastructure that fosters continuity of care during one of the most vulnerable times in the maternal-infant journey.**

# Landscape Analysis

A comprehensive review of existing hospital websites, nonprofit platforms, apps, podcasts, and awareness campaigns revealed a fragmented and inconsistent landscape of post-discharge resources for NICU families. Most hospital systems across Colorado maintain their own NICU support materials, but offerings vary widely in depth, accessibility, cultural representation, and usability. While some institutions offer relatively robust family-centered features (e.g., child life services, family navigators) and some hospitals offer peer mentorship via partner organizations such as [Love for Lily](#), others have limited or generalized information. Notably, very few digital tools or resources are shared across hospital systems, which can leave families — especially those who engage with more than one NICU—without continuity in care or guidance, adding one more thing to navigate.

National platforms and nonprofits such as the [March of Dimes](#), [Graham’s Foundation](#), and [Hand to Hold](#) offer rich content and structured peer support, yet families often don’t know which of these are trustworthy, locally relevant, or recommended by their NICU team. This abundance of resources can be overwhelming for parents seeking clear direction, particularly during a highly stressful transition from hospital to home.

Additionally, many hospitals reference authoritative sources such as the [American Academy of Pediatrics \(AAP\)](#) or [March of Dimes](#), but there is no unified framework for how or when to share these resources. A coordinated, hospital-endorsed resource library grounded in vetted materials from national leaders would help standardize the support experience and ease confusion for families navigating cross-system care and at-home support.

This analysis also uncovered that while there are numerous mobile applications targeted at NICU families, none provide a truly comprehensive, integrated platform. Examples of existing applications include:

- **[MyPreemie App](#)**: Offers practical checklists and emotional reflections but lacks integration with hospital discharge or follow-up protocols.
- **[Compass \(March of Dimes\)](#)**: Features NICU glossaries, trackers, and questions to ask—but does not include peer support or care navigation.
- **[NICU Companion](#)**: Allows families to track care and get information on breathing support, breastfeeding and diaper output and connect to hear parent stories, but is not designed for connection to local services or SDOH supports.
- **[NICU2Home \(AngelEye Health\)](#)**: Integrates with EHRs (Electronic Health Record) but is proprietary and dependent on system-level adoption.
- **[Hand to Hold App](#)**: Provides virtual support groups and educational libraries.



# Landscape Analysis



Despite their usefulness, these apps operate in silos, vary in functionality, and are rarely referenced during the NICU discharge process.

Despite their usefulness, these tools operate in silos, vary in functionality, and are rarely referenced during the NICU discharge process. Additionally, there is no current data to understand positive user experience and adoption rates. There is a clear opportunity to consolidate best-in-class features into a single, centralized platform that includes:

- Vetted, hospital-endorsed education (e.g., AAP, March of Dimes, etc.)
- Social determinants of health navigation tools (e.g., United Way 211, transportation aid, etc.)
- Peer mentorship, support circles, and culturally responsive content
- Care tracking, journaling, and discharge planning tools
- Multi-language access and trauma-informed resources

**Ultimately, NICU families do not need more content — they need clear guidance, continuity, and a trusted system to help them know where to turn.** A unified platform like Hello Home can serve as that central, scalable solution and also be a trusted resource if adopted during the discharge process. Further, hospitals and discharge support professionals could have the ability to track families' progress and identify possible areas to support families further.

# Colorado NICU Family and Professional Perspectives:

## In Their Own Words



### Summary of Process, Participants & Findings

To build on the quantitative data and landscape scan, Causeworthy conducted a series of surveys and interviews to hear insights and feedback from families and professionals involved with Colorado’s NICUs. We were fortunate to have stories shared by 124 parents via interviews and surveys, as well as 18 professional perspectives shared in interviews and fact-finding sessions in Summer 2024–Winter 2025.<sup>1</sup> This group of respondents is more representative of the Colorado and NICU populations than two key Colorado surveys related to birth and NICU experiences. Compared to other data sources, survey respondents were more racially diverse and had less education,<sup>2</sup> offering powerful insights into the experiences of the diverse families with NICU stays.

Overall parents reported positive NICU experiences and were happy to bring their babies home. However, feedback from parents and professionals points to places where the experience could be improved and challenges eased, reducing poor outcomes and high costs down the road. These stakeholders shared what went well during hospitalization, discharge, and post-NICU, as well as opportunities for change.

“We had a very wonderful and caring staff throughout the NICU. They went above and beyond and made sure everything was well taken care of for our baby and ourselves.

– Colorado NICU Parent

“If you had a term baby that was well, you would be in the hospital 24-48 hours, maybe. And then get sent home with this little person that has no instructions and can’t talk to you. And so one of the advantages of being in the NICU is that we are there to walk you through that whole journey and the nurses and even the docs, because we’ve got a very small medical staff as well...we’re all family by the end of it.”

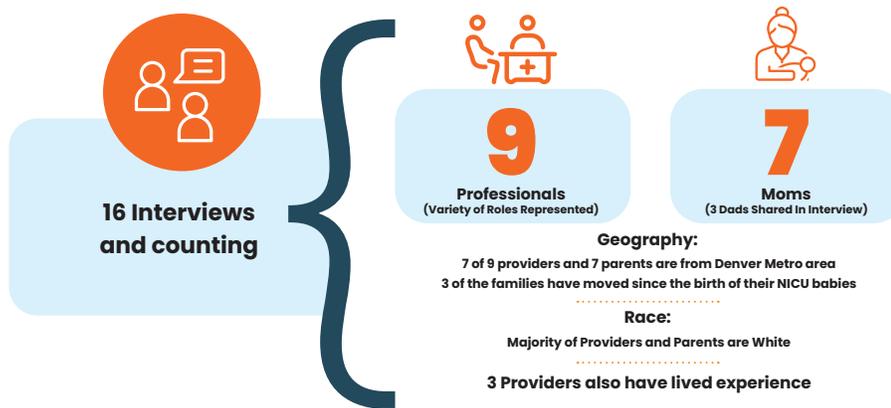
– Colorado NICU Professional

<sup>1</sup> Survey inclusion criteria required that parent respondents be 18 years of age or older and had an infant discharged from a NICU in the previous 6–12 months (now living or deceased). Professionals interviewed were recruited via convenience sampling such as referral by DEFINE partners; these were professionals who work with families during and/or after the NICU stay. Parents interviewed had experiences in Colorado NICUs, ideally within the last 6–12 months, however, some participating parents had NICU experiences farther into the past. Additional survey and interview documentation is available in the report appendices: [Survey Appendix](#), [Interview Appendix](#).

<sup>2</sup> This group of respondents is more representative of the Colorado and NICU populations than existing datasets, such as PRAMS or DEFINE’s quarterly cohort survey. In particular, this group has more varied educational experiences, skewing toward less education; participation by more fathers; and greater representation by race for BIPOC groups (American Indian/Alaska Native, Asian/Pacific Islander, and Black or African/American) compared to the other two surveys.

# Colorado NICU Family and Professional Perspectives:

## In Their Own Words



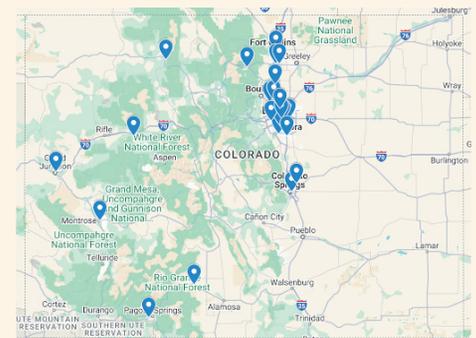
While interview participants were primarily white and located in the Denver metro area, survey respondents were more representative of the broader Colorado NICU population. In contrast, survey respondents were more representative of Colorado’s NICU families. This snapshot provides an overview of a “typical” NICU parent respondent from this survey:

- Traveled more than 30 minutes to the NICU (71% of respondents).
- Experienced a single NICU with this infant (75% of respondents; mean of 1.3 NICUs per respondent)
- Had other children at home during the NICU stay (65%, with an average of one other child)
- Had a singleton birth (68%)
- Had familiarity with the NICU (70% had some form of self or close previous experience. 44% had a family member with a previous NICU experience, 29% had a close friend with a previous NICU experience, and 18% had had their own baby in the NICU before. Those with previous NICU experiences may have past trauma when they return to the NICU. Many parent interview participants reported having not just previous NICU experiences, but losses there.)
- About half of NICU parents surveyed were married, with the percentage increasing slightly (48% to 53%, or five percentage points) from the time of birth to the time of the survey. Responses to open-ended questions highlighted the relationship difficulties a NICU experience can present to parents even if marital status does not change. Eight percent of parents surveyed were single parents.
- Survey respondents tended to be white (40%) and spoke English most often at home (73%)

One place where NICU parent experiences varied was by birthing hospital– respondents’ babies were born at

**27**  
hospitals across Colorado

**Fig. 1:**  
Survey Respondents Gave Birth at an Array of Hospitals Across Colorado



# Colorado NICU Family and Professional Perspectives:

## In Their Own Words

### Colorado NICU Families: Needs and Opportunities

In interviews and survey responses, parents with experience in Colorado NICUs – and the professionals caring for them and their babies – shared their perspectives on the NICU journey, noting peaks as well as valleys.

#### *Pressures and Challenges for Parents During the NICU Stay*

Some of the ways being a NICU parent is difficult during a baby's hospitalization include:

- NICU-itis (getting tired of the experience going on for a long time)
- Emotional Rollercoaster
- Isolation
- Lack of knowledge – not knowing what one doesn't know, not knowing what or how to ask providers questions
- Pressure of becoming an educator to family and friends
- Feeling of being behind – in knowledge and development of baby relative to health babies born at term

“I don't think they realize. I talked to them about it, but I don't think they realize what a rollercoaster it can be... there's an initial period that can be really frightening and their babies can be very sick and they stabilize, but that then there's these occurrences of other potential complications that happen later when they're more comfortable, which is really terrible.

**So it's that up and down nature of later disease, the later comorbidities that I don't think they know about.”**

– Colorado NICU Professional

“I cannot even imagine trying to navigate any of what we did as English, not being my first language, or not having the education level that I had or the family support. So I feel like I'm a competent human being with a lot of resources at hand. And I struggled constantly with knowing what to access and how to get help... I think what helps parents' mental health is knowing your basic needs are taken care of and your kids... have people organize [resources] so that you can feel more confident leaving the NICU.”

– Colorado NICU Parent



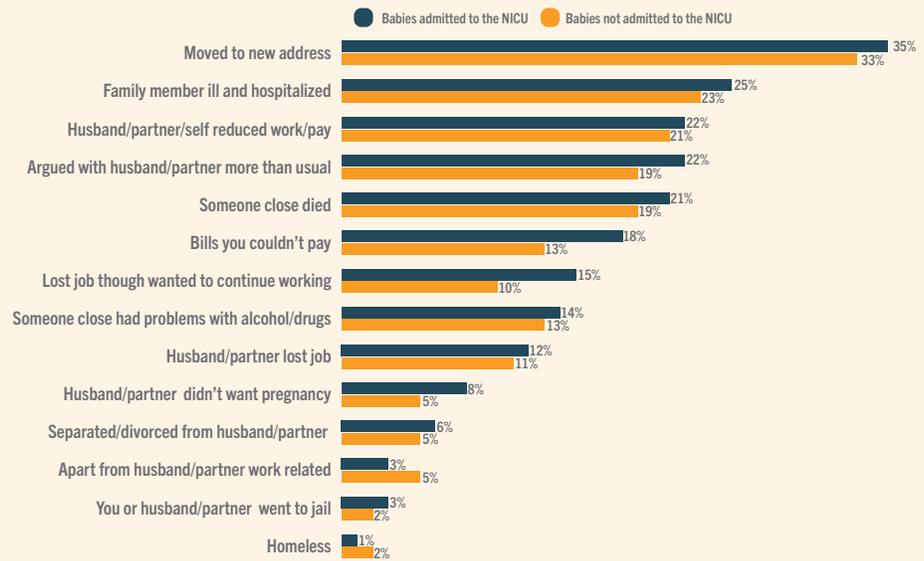
# Colorado NICU Family and Professional Perspectives:

## In Their Own Words

### Family Supports: Social Determinants of Health

Previous research on families' NICU experiences points to the ways in which systemic inequities compound the challenges of having an infant in the NICU. Many mothers experience significant stressors before their babies are born, including those whose babies go to the NICU (Fig. 2).

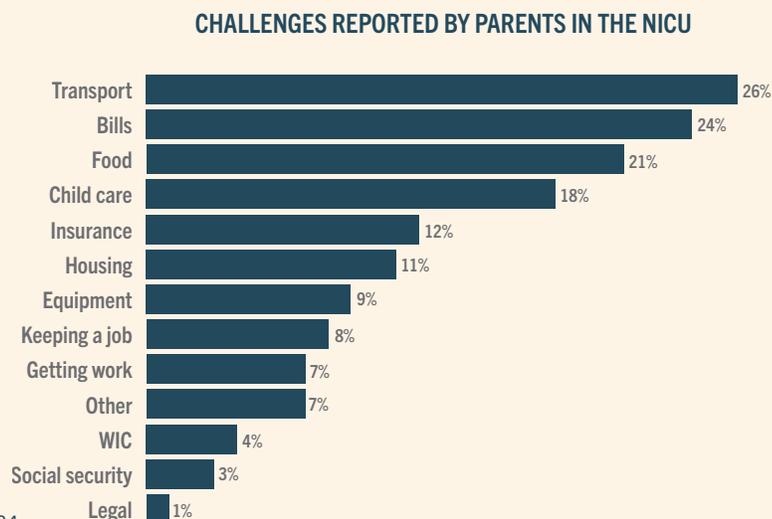
**Fig. 2:** Stressors in the 12 months before delivery were common among mothers whose babies were admitted to the NICU and those whose babies were not.



Source: 2020-2022 PRAMS Data.

Once the NICU experience is underway, transportation is a well-documented barrier to family presence and engagement at bedside. Employment, finances, and finding care for other children are among other challenges, as shown in Figure 3

**Fig. 3:** Transportation, bills and food were top-reported challenges experienced among parents in the DEFINE cohort while their baby was in the NICU.



Source: DEFINE Quarterly Cohort Survey, Q2 2024.

# Colorado NICU Family and Professional Perspectives:

## In Their Own Words

Our findings aligned with these trends. Interview participants reported these as top challenges for NICU families:

- Transportation
- Meals – varying support and restrictions
- Basic needs, especially for recently arrived immigrants

71% of survey respondents traveled more than 30 minutes to the NICU. Distance from the hospital can be used as a proxy for rurality and has been shown to impact parental engagement, as it hinders parents' ability to be at the bedside. Survey and interview feedback echoed previous research that **transportation to the hospital is a top barrier for NICU families.**

**71%**  
of survey respondents  
traveled **more than  
30 minutes  
to the NICU.**

Respondents spoke of protective factors that offset the challenges described above, such as supportive family and friends, supportive employers, and resources like the Ronald McDonald House and gas cards. However, they also noted that economic changes are impacting the availability of resources while driving up families' needs. Providers are aware of families' extensive needs and the increasingly difficult economic circumstances for families and work hard to offer supports but face limitations themselves, including limited system resources, provider time constraints, and burnout.

“In unit, the biggest barrier to families being educated by staff is being at the bedside, and that is about finances...[at one hospital] they feed their families two meals a day...which means both parents can show up and have two meals a day and be with their baby...families aren't allowed to bring food into [units and their rooms]...that creates a really big barrier for learning from staff.”

– Colorado NICU Professional

“We couldn't see him as much as we wanted to... because the buses that went from there, they stop at a certain time from the hospital. So if we wanted to see [our baby], we had to get an Uber. It wasn't exactly easy to find someone late at night...[at first] we spent a couple hundred dollars...on Uber.”

– Colorado NICU Parent

“Even though I can issue bus tickets to families, that doesn't mean that that is an easy journey for families. This mom may have just had a C-section and maybe shouldn't be walking to the bus stop... [Parents also have a] hesitation to utilize and take public transportation because of risk of infection in those spaces to then visit their child who's very fragile.”

– Colorado NICU Professional



# Colorado NICU Family and Professional Perspectives:

## In Their Own Words

### *Pressures and Challenges for Parents After the NICU Stay*

In addition to the many challenges of having an infant in the NICU, parents and professionals identified themes related to the post-discharge period for parents. These themes were continued from the hospitalization period:

- The pressure of becoming an educator to family and friends
- Feeling of being behind – in knowledge and development of baby relative to healthy babies born at term

New themes parents reported facing after bringing baby home were :

- Now I am the caregiver and the medical provider
- The NICU team became my family – and now that support system is gone
- Losses in independence – some cannot fly on airplanes or visit family far away, careers are impacted, feeding in public may be challenging or not possible
- Lasting trauma that may set in once the initial flurry of hospital activity is gone

“I think there is sometimes a perception that the NICU will be the hardest part, and then you go home and everything is normal...**there is no mom that’s ever been like, that was easy...** It’s usually just different. It’s adjustments. It’s just a different kind of hard.”

–Colorado NICU Professional

“I think parents are unprepared for [going] from this environment whether you like it or not, of having all of these eyes and hands and brains wrapped around caring for this child, Then it’s over and it’s a weird drop off, sort of like, ‘okay, well good luck out there’...**I think they’re woefully under-prepared for their own emotional responses to going home.** I think it’s confusing because on one hand, you’re so excited to be free from the NICU, and often it’s scary to not have that support. For some parents, I think they feel almost like a loss because depending on how long they’ve been in the NICU, they’ve developed relationships with this sort of medical team, and now they have to go find a new medical team. And then I think the emotional aftermath of living through a NICU hospitalization...**I have a colleague who [says] it’s like the tail of that comet is long...**”

– Colorado NICU Professional (*emphasis added*)

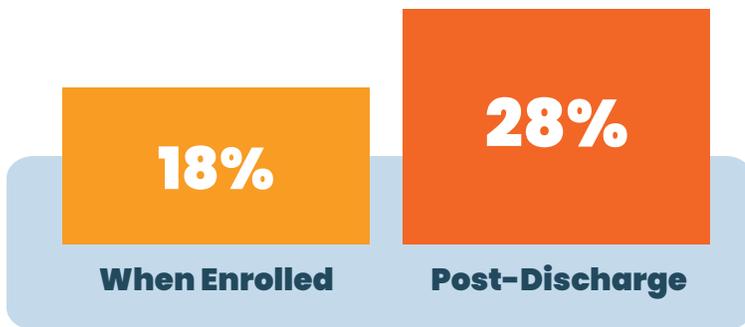
# Colorado NICU Family and Professional Perspectives:

## In Their Own Words

### Family Supports: Mental Health

The stress and trauma of a preterm birth, an infant with complex medical needs, or an extended hospital stay can easily impact the mental health of a parent. Rates of mental health diagnoses rose in parents in one recent survey from hospitalization to after discharge:

**THE SHARE OF PARENTS REPORTING THEY HAD A MENTAL HEALTH DIAGNOSIS ROSE BETWEEN ENROLLMENT AND POST-DISCHARGE.**



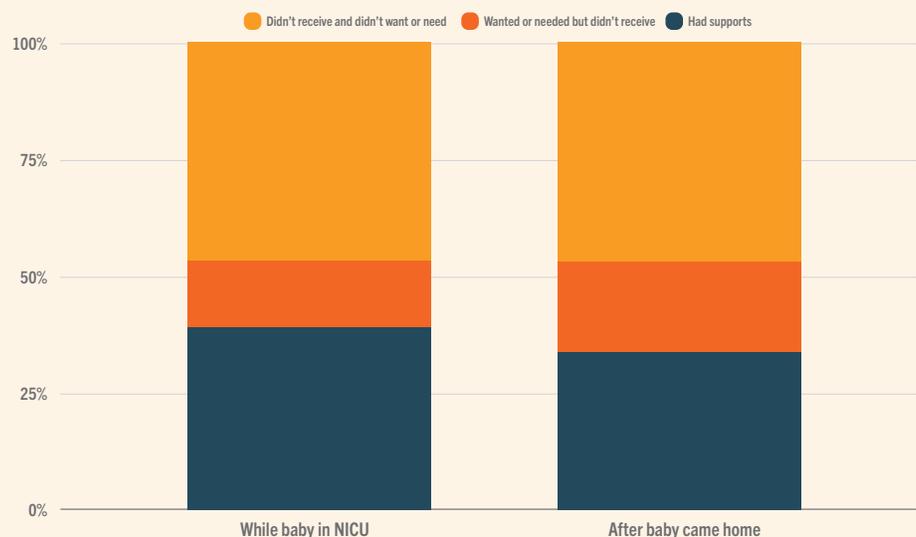
Source: DEFINE Cohort Survey Q1 2025.

“Having an infant in the NICU was an overwhelming experience associated with negative feelings. These included role strain, distress, and emotional pain (specifically, when parents were excluded from taking care of the infant and excluded from parental-infant proximity or closeness), and a sense of alienation. On the other hand, when parents were involved in infant care, were allowed proximity, communicated clearly and openly, and formed rapport with the nurses, they became more satisfied and confident in their parenting roles.”

– Obeidat, H.M., et al., 2009.

Our survey asked parents about mental health support received and/or wanted during and after the NICU period. The percentage of parents who wanted but did not receive mental health support went up slightly from baby’s time in the NICU (16%) to after going home (19%). The proportion of parents responding to our survey who had a gap in mental health support (wanted or needed care but did not receive it) grew slightly from the hospitalization period to post-discharge, as shown in Figure 4. Meanwhile, the percentage of parents who didn’t receive and didn’t want or need support remained steady.

**Fig. 4:**  
Professional Mental Health Support Wanted and/or Received, During and Post-NICU



# Colorado NICU Family and Professional Perspectives:

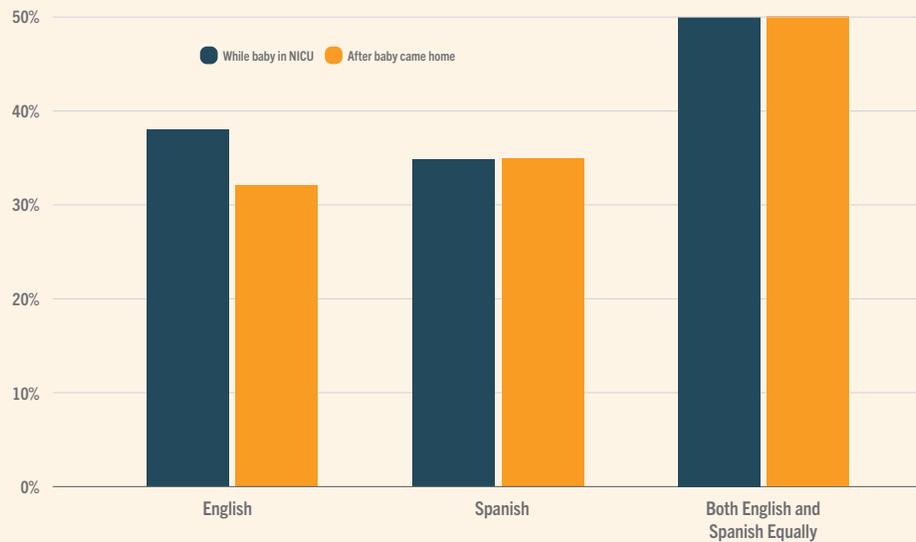
## In Their Own Words

A few additional takeaways include:

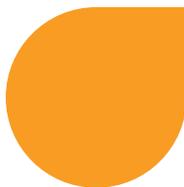
- Parents who were divorced at the time of birth were more likely to receive mental health support than others.
- A majority of parent respondents did not change their status of receiving or wanting mental health support from the NICU period to time at home. Twenty-four of 116 respondents (21%) had mental health support both during and after the baby's NICU stay. Seven (6%) wanted or needed mental health support during both periods but did not receive. Forty-four (39%) did not want or need support in either time period.

Figure 5 shows that dual language speakers (English and Spanish) were most likely to receive support during both time periods.

**Fig. 5:**  
Professional Mental Health Support Received by Language Spoken at Home



Parents noted the strain on relationships in addition to individuals:



**“Marital support for NICU parents would be huge. I am still married but our experience devastated our marriage.”**

– Colorado NICU Parent

# Colorado NICU Family and Professional Perspectives:

## In Their Own Words

Isolation was a major theme for parents who shared their perspectives. Parents crave connection with and advice from other parents, especially those with firsthand experience and knowledge of Colorado.

One way that hospital staff and other professionals serving NICU families can address these feelings of isolation is through sharing local and online support groups and connections to peer mentors. These connections can be made available in the recommended platform as well.

**“One thing that really bugged me was how we got zero information about local support groups or other NICU parents in our area. That isolation in those first months was pretty tough to deal with.”**

– Colorado NICU Parent

**“I needed a mentor who'd been through the NICU in mountain towns. Google didn't know rural clinics might mistake his NG tube for “weird jewelry.”**

– Colorado NICU Parent

**“I wish our NICU...had connected us with other local NICU graduate families before discharge. That first winter at home, I felt like we were the only people in the world dealing with a preemie and oxygen equipment during Colorado's cold and flu season.”**

– Colorado NICU Parent

**“One thing I really missed was a peer mentoring program that paired me with another parent who had successfully navigated the shift from NICU to home life.”**

– Colorado NICU Parent

The post-discharge period can be particularly challenging. Bringing a baby home from the NICU is a major transition that can be both exciting and daunting. The next section highlights possibilities for supporting parents through the challenging journey from hospital to home.

# Themes and Proposed Solutions

Based on voices of lived experience, NICU parents need support to:

- **Reduce feelings of isolation** through:
  - › Peer mentorship referrals
  - › Virtual support circles, storytelling
  - › A NICU community calendar
- **Empower mothers in care coordination** through:
  - › Customizable care trackers for feeding, medications, sleep patterns, and developmental milestones
  - › Digital discharge and follow-up checklists
  - › NICU video libraries and accessible resources for siblings and family members
- **Support mental health** through:
  - › Mental wellness check-ins and logs
  - › Screening tools with automatic referrals to professionals
  - › Virtual counseling referrals (e.g., Connections Program)
  - › Self-care and parenting tips



Hello Home will address the existing lack of support for families transitioning home after a NICU stay. The platform addresses feelings of isolation, overwhelm, and lack of resources within a user-friendly, web-based platform. It offers referral services optimized for rural and low-bandwidth areas, a local resource directory, culturally responsive and inclusive materials for diverse populations.

## *Preference for Visual & Hands-On Learning*

Parents shared how they prefer to learn new information. In the survey, the most preferred method was **watching someone show how to do something** (40%), followed by **seeing pictures or diagrams** (26%). Only 15% of parents selected reading as their preferred learning mode, indicating the handouts many families receive in hospital NICUs may not be the best communication method. However, several parents did comment on a desire for more things in writing to review or absorb later due to fatigue and information overload at the hospital. Others wished there had been more instruction during hospitalization.

“I would have asked for all the information in writing. The nurses at [Hospital name] told me so much while I was exhausted, and I forgot half of it by the time we got home.”

– Colorado NICU Parent

“I should’ve taken more videos of the nurses demonstrating how to use the equipment. Reading instructions at 3 AM while trying to figure out the oxygen monitor was not fun at all.”

– Colorado NICU Parent

“Why didn’t anyone tell me to photograph medical gear setups at the hospital? Replicating it at home took days of trial and error.”

– Colorado NICU Parent

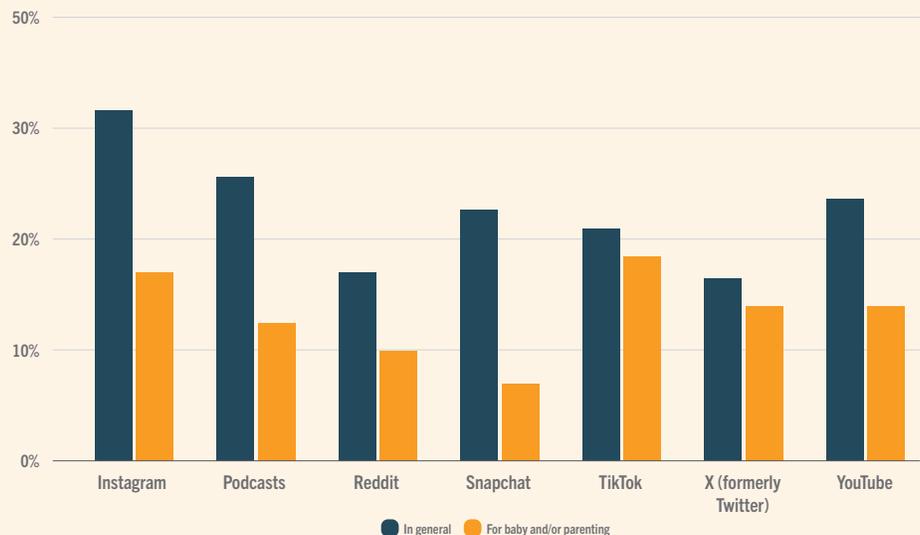
# Themes and Proposed Solutions

## Need for a Go-To, Accurate, Trusted Source

While 30% of respondents (n=35) reported having a favorite source of information for NICU parents, they shared 30 different resources of various types, from Colorado and beyond. No single source emerged as a trusted or go-to resource for most parents<sup>3</sup> relied on or recommended. In addition, no parents reported using NICU-focused websites.

In addition to websites and social media, respondents reported going to an array of people and sources for support and/or information. Top responses were: Friends (39%), Family members (36%), and Books (35%), closely followed by healthcare providers, parenting classes, and places of worship (such as church or synagogue), with 34% each.

**Fig. 6:** While NICU parents were most likely to use Instagram, Podcasts, and YouTube for general social media use, they were less likely to use social media for baby and/or parenting. Among social media platforms, TikTok was the primary source of information related to babies and/or parenting.



Parents reported using social media and other resources for the NICU for a variety of reasons:

- Support with resources (19%)
- A sense of community (19%)
- Emotional support (15%)
- Entertainment (16%)
- Education (14%)

Interview feedback indicated that NICU professionals typically aren't aware of evidence-based social media accounts or websites and face restrictions on what they can share due to hospital liability concerns. In some settings, hospital policies banning paper in rooms limit information-sharing. NICU professionals also voiced concern that previous lived experience can sometimes be a barrier to receiving information and parents turning to unreliable accounts on TikTok for incorrect advice.

For families receiving care in multiple NICUs and hospital systems, sharing of information and consistency can be challenging. Finally, fear and mistrust of the healthcare system due to past negative personal experiences and/or systemic racism can pose challenges in connection and communication.

<sup>3</sup> Question wording was "Do you have any favorite pages, influencers, podcasts, or other social media sources for other NICU parents?"

# Themes and Proposed Solutions

## Language Matters: Accessibility

In addition to sensitivity in word choice and phrasing, language accessibility is key. In our survey, 9% of parents spoke English and Spanish equally at home, and 19% of parents mostly spoke a language other than English at home.<sup>4</sup> Interview subjects named more than ten languages spoken by families in the NICU, and countless NICU professionals noted the challenges of family-provider connection when English is not the parents' first and/or preferred language. Not all hospital tools, such as iPads, include all languages and dialects spoken by families. Translated content will help to bridge these gaps.

"A lot of [Spanish-speaking families] don't know what a NICU is. It's not something that's super familiar... Even the acronym NICU and how it's translated into Spanish is very new to the Hispanic community. So a lot of them I know feel very overwhelmed, very lost in terms of why they're in this specific unit."

– Colorado NICU Professional

"As parents who don't speak English as our first language, we needed more cultural support and translation services during our hospital stay... especially around feeding customs and traditional postpartum practices from our culture."

– Colorado NICU Parent

"The language barrier was huge for us. Next time, I'd insist on having a Spanish interpreter present for every important conversation at [hospital], not just when they remembered to call one."

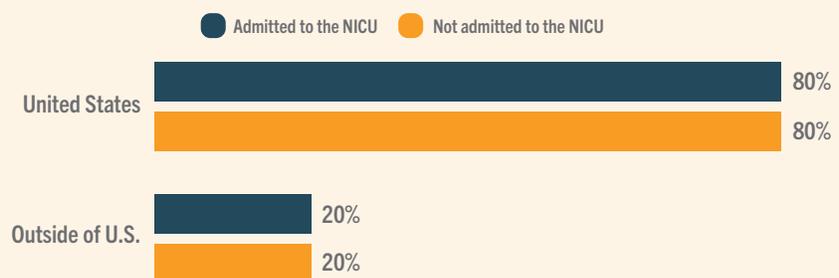
– Colorado NICU Parent

"Most hospitals have an iPad translator. We used to have real people... having a person stand next to us to talk to a family in their native language is so different... it's not ideal for so many families when you go home. I actually think it gets harder because at least in the unit, you have an iPad translator in your room all the time when you are scheduling your appointment. For example, if the person only speaks English, guess what? It's really hard to schedule your appointment depending on what county you live in, your [Early Intervention] provider may not speak your native language and they're going to come in your home and try to explain to you in as good of a way as we all try, right? Google translate can be very effective. I use it myself, but it's not the same as we've seen an increase in both French and Swahili speaking families in the Denver area. That's been a really big challenge because there's not, well Swahili specifically, the iPad doesn't do it, so we don't have that option."

– Colorado NICU Professional

**Fig. 7:** One in five babies admitted to the NICU or born pre-term was born to a mother from outside the U.S.

MATERNAL COUNTRY OF ORIGIN BY NICU ADMISSION, 2023



Source: 2023 Colorado Vital Statistics Data.

<sup>4</sup> In the most recent DEFINE cohort survey (Q1 2025), 9% of respondents preferred a language other than English or English and Spanish.

# Themes and Proposed Solutions



NICU professionals expressed support for interpretation for families while acknowledging some challenges of implementation on a consistent basis. These challenges included difficulty locating a digital device for virtual interpretation, extra time needed for interpretation in a stressful, time-intensive setting, and parents speaking dialects that hospitals and language lines don't serve.

**“Needing an interpreter is always a barrier... the provider’s doing rounds, family A needs an interpreter, so the provider says, okay, I’m going to go to family B and so on, and then wait for the interpreter. But then sometimes that’s not communicated to the family, so then they feel like they’ve been skipped. In the meantime, they might need to do tests, so then the lab comes in and does the test, but the provider didn’t do the rounds to let them know that they were going to do the test. So pushing that out sometimes is a challenge, and I know they’re looking at addressing it...rounding is the big portion of when a lot of information is provided in terms of treatment condition, things like that. So if that gets pushed out, then the families are kind of in limbo.”**

– Colorado NICU Professional (*emphasis added*)

# Additional Platform Considerations

Parents' own words about what would have been helpful can inform the platform further:

"My one change would be to switch from impersonal data packets to interactive video call check-ins, so I could see and hear his progress clearly whenever I needed reassurance."

– Colorado NICU Parent

"Clearer guidelines on when to return to the ER versus calling the pediatrician would have saved us midnight panic trips."

– Colorado NICU Parent

"I wish they'd given me a daily schedule template or app to track all the medications and feeding times. Those first few weeks were such a blur, and I kept second-guessing if I'd given the right meds at the right times."

– Colorado NICU Parent

"Regular check-ins from a NICU transition coordinator could have spotted warning signs we didn't recognize as first-time parents."

– Colorado NICU Parent

"The discharge paperwork was way too overwhelming – like 20 pages of medical jargon. A simple checklist or visual guide would've been so much better for sleep-deprived parents like us."

– Colorado NICU Parent

## Needed Elements

Looking across survey responses, interviews, the landscape of NICU offerings, and quantitative data on NICU families, the following are key elements needed to serve NICU families through and following hospital discharge:

- A single, central source of information
- Well-organized and easily searchable
- Interactive & responsive
  - › Available for questions & messaging 24/7
  - › Early warning / Determining what's an emergency
  - › Documentation to refer back to
- Sustained connection to NICU
- Updated in real-time
- Simple and easy to digest
- Robust tools and information
  - › Trackers for medication and feeding
  - › Information on how to understand developmental milestones
  - › Navigation supports, such as care coordination and appointment scheduling, as well as help managing equipment

"I had no clue how to navigate the maze of follow-up appointments after discharge! My baby had six different specialists to see, and coordinating all that care while living up in the mountains... was a logistical nightmare that I wasn't prepared for."

– Colorado NICU Parent

"I wish we had more information about what to expect in terms of developmental delays. After our son started physical therapy a week after discharge we were surprised when they told us how far behind he was after we were just told how well he was doing while in the NICU."

– Colorado NICU Parent

"I really would have appreciated detailed instructions on how to manage ongoing medical needs-like oxygen support or medication schedules – right at home."

– Colorado NICU Parent

# Additional Platform Considerations

## Product Format, Delivery & Messaging

### Key Considerations for Format and Delivery

Family and professional feedback points to the following key considerations for product or platform format and messaging to support families:

- Parents prefer to learn with their eyes and experience face time constraints due to juggling work and family. **Hands-on demonstrations and images seem to be most helpful**, and should be accessible on parents' own timelines, and able to be visited multiple times.
- **Trust is crucial yet hard to come by.** Parents trust professionals they get to know in the hospital, and sometimes other parents in online groups. **Guidance should come from those with lived experience, whether professional, personal, or both.**
- **Vetting is needed to ensure reliability of information and streamline content.** Both audiences need help culling the volume of potential accounts and sources to determine what is accurate, reliable and relatable.
- **Engage parents early and often.**

"I wish I'd known about parent support groups sooner. Other moms' advice was way more helpful than hospital handouts."

— Colorado NICU Parent

### Specific Strategies to Engage Parents Early and Often

Three considerations for parent engagement and discharge preparation content delivery that emerged in this research were:

#### 1. Timing: Discharge begins the moment families enter the NICU

- In the first 2-3 days parents are in shock and dysregulated and should receive only the most basic information
- Over time, parents can receive more nuanced information, but still in small quantities
- Content can be broken out week by week and repeated over time

#### 2. Dosage

- Tie the length of content to things NICU parents are already doing, like a skin-to-skin session or a pumping session

#### 3. Family Inclusion in the Care Team

- Provider openness to feedback
- **Parent Idea:** Feedback cards at charge nurse station for concerns, preferences, and comments with anonymous option. Parents don't always know who to approach or how when they have concerns, but offering them clear pathways for feedback can boost their engagement.

# Additional Platform Considerations

## *Empowering Messages*

Many parents expressed being surprised with themselves, speaking to a newfound sense of self-efficacy and self-determination. They shared anecdotes of resilience, creativity, and perseverance such as:

“I discovered I’m a paperwork ninja. Mastered Medicaid appeals while pumping in a [Hospital name] broom closet.”

“That period in the NICU revealed to me the power of perseverance and showed how pushing through even the darkest times can lead to unexpected strength.”

“Going through the NICU chaos made me realize how resourceful I can be, finding answers even when everything felt overwhelming.”

“I found out that my ability to advocate for my baby is one of my greatest strengths — I’m not afraid to ask questions.”

An effective platform will build on this resilience and newfound sense of empowerment, offering frequent, short messages of encouragement and validation once parents are home on their own. Mental health check-in messages could also identify needs early and provide support.

## *Addressing Concerns Unique to Coloradans*

Colorado-specific knowledge and messaging are essential. There is no single resource or support specific to Colorado. While national organizations such as the American Academy of Pediatrics and the Centers for Disease Control and Prevention provide reliable guidance, survey respondents identified challenges specific to the Centennial State that they weren’t prepared for when they got home, such as managing oxygen and intense sun for baby at elevation, and quality of drinking water in rural locations.

“How to keep medical gear charged during Rockies power outages. Backup batteries saved us.”

“I’d beg for a direct line to our NICU nurse for the first week home. Google didn’t know our Colorado altitude quirks.”

“The altitude thing caught me completely off guard. Our baby did fine with oxygen in the [Hospital name], but once we got home to Leadville at 10,000 feet, his oxygen saturation dropped, and we ended up back in the hospital. I wish someone had explained how elevation might affect his breathing.”

“I wish I’d known how to sanitize gear with well water. Our cabin’s iron-heavy tap turned his NG tube orange, and the nurse thought it was rust.”

# Additional Platform Considerations

## Other Ideas to Streamline Care and Discharge

In surveys and interviews, NICU parents and professionals shared additional ways to further integrate parents and healthcare professionals and improve education. Suggestions to overcome gaps between parents/caregivers and medical providers included:

- **Take Notes with an AI Scribe** – Utilize artificial intelligence to help break down medical jargon for NICU journey and post-discharge. Add links to videos where applicable that are teaching moments so families can revisit content at will.
- **Improve and Standardize Language Access** – Explore ways to make practices consistent so all families can receive communication – in their preferred language – at key points in the journey
- **Share Resources among Hospital Systems** – Build on the many great things already happening by offering ways to share existing tools and smooth differences in systems for families if transferred. 24% of our survey respondents experienced more than 1 NICU, and many more were transferred from a birthing hospital without a NICU to a hospital that had a NICU. Also, foster clinician introductions and convenings to build community, combat burnout, and ease patient transfers.
- **Highlight and Clarify Differences between Hospital and Home Before Discharge** – Examples include sleep practices and specific machines that are not identical and catch parents off guard

“Our families...hate when they get transferred and have to go to big city hospitals and it’s scary for them... that’s one thing maybe that we could help with. Just knowing what’s out there at the other facilities... to say...these are some things you can look for or some people you could look for would be really helpful.”

– Colorado NICU Professional

“I needed more guidance on setting up a safe sleep environment at home tailored to premature infants, beyond the general advice everyone gives.”

– Colorado NICU Parent

“I wish someone had taken more time to explain SIDS prevention beyond just “back to sleep.” As first-time parents living in a rural area..., we were terrified and confused about safe sleep practices.”

– Colorado NICU Parent

“I mean, they told us “back to sleep,” but there’s so much more to it that I had to figure out on my own after we left.”

– Colorado NICU Parent



# Platform Development

## **A Phased Approach to Platform Development**

The development of Hello Home followed a deliberate, phased approach grounded in human-centered design and shaped by both the qualitative and quantitative research. Each phase outlined below was informed by the lived experiences of families and the clinical insights of NICU providers. This structured process supports the initial implementation of Hello Home as a pilot across five DEFINE Colorado hospitals, with a focus on iterative refinement based on user feedback and continuous improvement to optimize the platform for broader scale.

### ***Phase 1: Discovery and Research***

During the discovery phase, the DEFINE Colorado team partnered with families, NICU providers, and researchers across multiple NICU sites to identify the unmet needs of families transitioning from hospital to home. Through surveys, structured interviews, and observational insights, the team uncovered several consistent pain points: loss of community, lack of continuity in care, confusion about available resources, and heightened emotional and economic stress. These insights revealed that many families felt overwhelmed and undersupported in the weeks and months following discharge.

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### ***Phase 2: Prototype and MVP Development***

Informed by these findings, the Hello Home concept will be transformed into a scalable, web-based platform. A minimum viable product (MVP) will be developed to centralize emotional support, care coordination and behavioral health resources in an accessible digital format. Core features included customizable care trackers, digital discharge checklists, symptom checker tools, peer mentorship, educational libraries and mental health screening with automated referrals. These elements will be designed to be culturally inclusive, trauma-informed, mobile-friendly and responsive to the specific needs of rural, LGBTQ+ and culturally diverse families.

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### ***Phase 3: Pilot Implementation and Iterative Feedback***

With support from DEFINE Colorado and the Colorado Perinatal Care Quality Collaborative (CPCQC), Hello Home is intended to be piloted across five diverse Colorado hospitals. These pilot sites represent a mix of urban and rural facilities, ensuring feedback from families with varied lived experiences. Implementation includes user feedback loops such as engagement tracking, parent surveys and provider interviews. Findings from this pilot will then be used to refine platform functionality, content and integration workflows.

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### ***Phase 4: Statewide Expansion and National Readiness***

Upon successful completion of the pilot, the initiative will expand across the DEFINE network, targeting additional NICUs throughout Colorado. Simultaneously, the team will prepare the platform for broader dissemination through the development of training modules, onboarding materials and partnerships with national organizations and healthcare systems. The platform's modular design, multilingual capabilities, and emphasis on interoperability will support its national scale-up.

# Why Build Hello Home

The transition from NICU to home is one of the most vulnerable and disorienting periods in a family's journey. While the NICU provides structured, high-touch care supported by a team of providers, the post-discharge experience leaves many families feeling alone, anxious, and underprepared. For families of color, those in rural communities and parents facing economic hardship or mental health conditions, these challenges are compounded.

Hello Home fills a critical systems gap by offering holistic, trauma-informed, and culturally responsive care navigation at scale. It provides:

- Peace of mind for families navigating complex and often unfamiliar healthcare systems.
- Tools to reduce NICU readmissions and ensure better follow-up care adherence.
- Operational relief for hospital discharge teams, who often lack the time and tools to connect families to community-based supports.
- A demonstration of equity in action through the inclusion of marginalized and underserved populations.

Fundamentally, Hello Home is not just a platform — it is a necessary extension of care that meets families where they are and ensures they are not left behind at discharge.

# Performance & Impact



The transition from NICU to home is one of the most vulnerable and disorienting periods in a family's journey. While the NICU provides structured, high-touch care supported by a team of providers, the post-discharge experience leaves many families feeling alone, anxious, and underprepared. For families of color, those in rural communities and parents facing economic hardship or mental health conditions, these challenges are compounded.

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# Performance & Impact

To measure success and inform continuous improvement, Hello Home aligns with the Proctor Implementation Framework and incorporates both implementation and outcome metrics. Key performance indicators (KPIs) will be collected at both the family and hospital levels.

## **Platform Engagement and Use**

- Percentage of families enrolled and actively using the platform post-discharge
- Frequency of feature usage (e.g., care tracker, discharge checklist, symptom checker)
- Participation rates in peer mentorship and virtual support circles

## **Health and Development Outcomes**

- NICU readmission rates within 30–90 days post-discharge
- Adherence to follow-up appointments (pediatrician, specialist, postpartum care)
- Early identification of developmental delays and connection to intervention services

## **Mental Health and Emotional Support**

- Completion of mental health screenings (e.g., EPDS, GAD-7)
- Referral and access rates to counseling and teletherapy
- Self-reported changes in maternal stress, confidence and feelings of isolation

## **Operational Efficiency and Cost Savings**

- Reduction in hospital staff time spent on follow-up and coordination
- Decreased unnecessary emergency visits
- Cost reductions through proactive care navigation

## **Equity and Inclusivity**

- Utilization rates among rural, LGBTQ+, and culturally diverse families
- Engagement with multilingual content and inclusive resource directories

These KPIs will be monitored through a combination of platform analytics, parent surveys and feedback from providers and care teams.

# The Strategic Why

**Hello Home does not exist in isolation — it sits at the intersection of maternal health, early childhood development, mental health and healthcare equity.** As such, several strategic considerations should guide its continued development and implementation:

- 1 Align with Early Childhood Systems:** Integrating Hello Home with early intervention programs, home visiting and early childhood education systems will allow for seamless tracking of development, school readiness and family well-being across the child's first five years.
- 2 Bridge the Maternal-Infant Dyad:** The platform should be positioned not only as a tool for supporting infant health but as a critical maternal mental health intervention. Supporting the caregiver is fundamental to supporting the child. Too often, postpartum care shifts entirely to the infant, leaving maternal well-being overlooked. Hello Home offers an opportunity to rebalance that focus—recognizing that a healthy, supported mother is essential to a thriving child.
- 3 Strengthen Community and Policy Infrastructure:** Hello Home can serve as a population-level intervention that informs state policy on maternal mental health, discharge planning, and digital care navigation. It can support case-making for Medicaid reimbursement and state-level investment in family engagement tools.
- 4 Invest in Voice and Visibility:** Storytelling from NICU families must remain central. Real stories break stigma, increase engagement and elevate the voices of those too often left out of the healthcare landscape.

# The Path Forward

To fully realize its promise, the next phase of Hello Home should include:

- **Comprehensive Evaluation:** Finalize data-sharing agreements and conduct a 12-month evaluation of pilot sites using mixed methods. Focus areas should include maternal mental health, infant health outcomes and user experience and engagement.
- **Enhanced Personalization:** Leverage AI or logic-based tools to tailor platform content and referrals based on infant diagnosis, family location, language preference, and psychosocial needs.
- **Cross-System Integration:** Create interfaces and referral pipelines with state early intervention programs, postpartum mental health providers, and pediatric medical practices.
- **National Readiness Planning:** Develop an adoption toolkit for other states or hospital systems, including marketing materials, training assets, and evidence summaries.
- **Campaign Activation:** Launch a public awareness campaign to elevate the importance of post-NICU support and maternal mental health. Utilize storytelling, digital content and targeted outreach to mothers, families and health care providers.

Hello Home is poised to become a national model for post-discharge family support. Its thoughtful design, research-based development and alignment with maternal-child health systems make it an impactful, scalable solution for one of the most critical and often overlooked stages of care and one of the most vulnerable populations.

# Appendix

To access our findings, please click on the links below:

- [Parent & Professional Interview Summary & Findings](#)
- [Parent Survey Summary & Findings](#)