**Washington State Birth to One Program: Building A Strong Foundation**

## **Working With Diverse Families**

While the transition from Neonatal Intensive Care Unit (NICU) to home is stressful enough for most new parents, navigating multiple systems of care for families who have Limited English Proficiency (LEP) creates barriers and confusion around the process. These differences in language, as well as potential cultural, religious, and ethical value differences, can create a block for these families in being full participants in their baby’s care plan. Other factors can be differing levels of health literacy, assimilation and acculturation factors, and potential unfamiliarity with western medicine/culture that need to be accurately accounted for when developing the plans for transitioning to home. There is no streamlining this process, without causing these families to be even further marginalized. Overlooking or delaying the provision of adequate language support exacerbates the barriers around understanding what is needed in the complex care of their child. It also restricts the family from being able to adequately express their needs and their own culture and decisions around caring for their child so that those aspects can be incorporated into the transition planning. The information presented below shows the model the Birth to One CoIIN project used to try and mitigate these challenges for those LEP families participating in the program. It will also provide information around some significant gaps in equitable care that were observed in building the program.

*“NICU families need to be held during their transition to living at home, the landing made softer, so they don’t fall off the cliff.”* Arlene Smith, Seattle Parents of Preemies

**Roadmap:**

Creating an individualized “roadmap” in each family’s primary language provided a centralized place families could see who was on their child’s care team. 25 out of our 150 families received a roadmap and other Birth to One documents in languages other than English (i.e., Spanish, Vietnamese, Amharic, Oromo, Marshallese, Mandarin, etc.). Having a single point of contact Community Resource Care Coordinator (CRCC) with access to the hospital’s interpretation and translation services enabled us to extend this intervention to non-English speaking families.



Components of the program that helped bridge some of those gaps are seen in the Road Map process and supports provided by the hospitals Community Resource Coordinators and the Peer Family Navigators

**Individualized intervention:**

* Meet families with LEP (Limited English Proficiency) in the hospital with an interpreter to explain the Birth to One program.
* Collaborate with the family’s inpatient Seattle Children’s Hospital case manager, social worker, or [patient navigator](https://www.seattlechildrens.org/clinics/patient-navigation-program/) to coordinate resources and discharge plan.
* Each step in the roadmap (public health Children with special Health Care Needs (CSHCN) coordinator, medical home, Birth to Three early intervention, nutrition home, parent support, and community resources) was explained in detail so families felt empowered to make their own informed choices.
* Families received the roadmap in their primary language, as well as in English, to share with providers.
* Birth to One CRCCs and the Peer Family Navigators took the time to contact each member of the child’s care team to better understand the process of contacting the clinic or provider in the family’s language (i.e., access to interpreters) when building the road map. This ensured that the information on the roadmap was clear and accurate.
* Birth to One CRCCs served as cultural liaisons across hospital systems including the providers and therapy services by bridging the language access needs and providing support for cross collaboration between the family and their child’s care team.
* Providing families with a single point of entry and multiple modalities of communication including video call, texting, email, and postal mail.
* Extended support through the Peer Family Navigators that with the continuation of interpretive services, allowed for continued bridging for the families with hospital staff.

Common gaps that came to light in this project are documented below. Some of these the program was able to address in the interventions and extended support and some are gaps to be addressed long term within a hospital or clinic setting.

1. **Difficulties in accessing services**
* Patient story example: Family needing to leave a message with their pediatrician would call the interpreter line and wait hours until one was available. The family either ended up having to leave a voicemail with the clinic or receive a call with the interpreter days later, leaving the family to find a solution and fend for themselves.
* Patient story example: CRCC called Medical Home Primary Care Provider (PCP) using interpreter line provided to family which utilized their hospital affiliated interpreter who was unfamiliar with pediatric clinic.
* Families would receive a different interpreter each appointment leading to the need for the family to provide a repetition of information of the infant’s medical history and concerns, it also required time for the interpreter to do a re-assessment of health literacy levels to adjust language, etc. creating further stress and trauma for the family.

Families not receiving information about the value of early intervention in their native language often leads to misunderstandings of services thus furthering distrust and distancing them from medical providers and care team staff. The Community Resource Coordinators and Family Navigators began to work on ways to disrupt the patterns of interaction with families by hospital and clinic that were barriers to families getting the support they needed to care for their child and learn how to navigate this new complex world of having a child with significant healthcare needs and/or disability.

1. **Language matters**
* The use of developmental screenings that are not culturally informed and don’t consider cultural and family practices or the families health literacy and awareness of western based developmental expectations are confusing and make it difficult for families to see the need for these interventions.
* The infant’s developmental levels and needs in physical, cognitive, communication, social/emotional, and adaptive areas can at times, conflict with those of the family’s cultural expectations and/or understanding creating barriers to follow through that put the family at risk for referral.
	+ Using negative connotations rather than strength-based when talking about a child’s medical/developmental or mobility impacts (i.e., special needs, cognitively delayed, communication deficit, abnormal eye contact, genetic abnormality, failure to thrive, or disability).

This is true for any family dealing with a new diagnosis but the added complexity of culture, language, the negative ablest language can be devastating and socially isolating.

* Explaining the developmental milestones for what constitutes as “normal” without explanation of the why of the milestones and a check for understanding and their families’ expectations for their child. Things such as: hunger cues, eye contact, sleep routines, and/or feeding/nutrition.
* Recognition of when cultural norms such as talking about breast and bottle feeding is considered a private matter that was not to be discussed. Finding alternative ways that preserve and honor the family’s dynamics and cultural needs to inquire about a child’s feeding habits so providers don’t just assume feeding is going well but in fact the family is struggling.
1. **Service modality of navigation that supported cultural and socio-economic barriers**
* Virtual modality for services: Finding alternatives when a family was not agreeable to telehealth services as service appeared less valuable or when technology was a barrier.
* Providers misinterpreting intent of families who decline services—providers had prioritized things that were not a priority to families and finding ways to bridge these differences for the care of the child.
* Bodily autonomy: Family not agreeable to Early Intervention services providing physical therapy to their infant was against their cultural healing beliefs for fear of moving their child in a way that they weren’t “naturally born to move”. Working with a family to understand the context of Early Intervention or therapeutic services in a way that adapts to the family’s cultural norms.
* Allowing time for a Community Resource Coordinator and/or a Peer Family Support Specialist to research a family’s indigenous language to find out more about the cultural implications of serving the family allows for family/child centered care.
* Making sure the interpreters are providing accurate unbiased information and that the families understand the why and how of instructions and information.
* Patient story example: Family being told their child was developmentally delayed and in the patient’s language it translated to “your child has mental problems”.

Not assuming that a family understands the nuances of managing their child’s healthcare or that they don’t have additional complications such as are highlighted below...

* Family didn’t know they could schedule multiple outpatient specialty appointments on the same day. This allowed the family to better coordinate appointments so that driving from Eastern Washington could be reduced to one trip instead of four or five. This is an example of how the family support model helped to address some of the barriers and inherent biases within the system that set families up for “failure”.
* The mother of a NICU baby who did not often visit was labeled by staff as incapable of caring for the child which can put a family at risk for being charged with neglect.
	+ Community Resource Coordinator learned mother was trying not to lose her job as she had taken days off already and feared not being able to pay for child’s hospital bills and talked with attending staff about the extenuating circumstances.
* Providers unaware of family’s living situation with 10+ family members in hotel and the baby was scheduled for heart surgery.
	+ Community Resource Coordinator communicated between providers and connected family with SCH social work. Family was able to secure down payment for an apartment and pushed the surgery out until they were safely moved.
* Family declined Birth to Three Early Intervention Services due to fear of “cost”.
	+ Community Resource Coordinator explained this service was free for them based on their qualifying income.
* Family wanted to make an appointment at a hospital’s Neurodevelopment Clinic and was told of a 6-month waitlist.
	+ Community Resource Coordinator placed a referral to an even closer neurodevelopment center (Mary Bridge) and the patient was seen a month later.
* Family was commuting by taxi to and from home/Seattle for outpatient appointments.
	+ Family was on Medicaid and Community Resource Coordinator set them up with Medicaid transportation services at no cost.
* Family kept being a no show for appointments.
	+ Hospital had wrong contact information for the family and no one checked.
	+ Family used the phone’s minutes/data and had the phone shut off mid-month.
* Family didn’t know SCH had multiple specialty [regional clinics](https://www.seattlechildrens.org/healthcare-professionals/access-services/ambulatory-services/specialty-clinics/) (East-Bellevue, North-Everett, South-Federal Way, Central-Olympia, rural-Tri-Cities and Wenatchee, etc.)
	+ Family was able to see a neurodevelopment provider one hour away instead of driving to Seattle (4.5 hours) through coordination with the Community Resource Coordinators and Family Navigators.
* Family didn’t know the difference between [Emergency Room and Urgent Care](https://www.seattlechildrens.org/clinics/urgent-care-clinic/emergency-or-urgent-care/) (translated to Spanish and Arabic).
	+ Community Resource Coordinator provided education and emailed family SCH resource in Spanish and the Family Navigator reinforced the lessons and navigating when one might be preferred above the other.
* Spanish speaking mother was following the same feeding plan 3 months after the child was discharged.
	+ Community Resource Coordinator communicated this directly to SCH nutritionist who called mother right away, modifying feeding plan and sending a copy to child’s PCP and Birth to Three agency.
* Family was discharged to a naval/army base and was not referred to the public health CSHCN program or Birth to Three Early Intervention due to the assumption of family having private access to those services on base (this is not necessarily the case).
	+ Placed CSHCN public health nurse referral with the installation so that the nurse and Birth to Three support were able to get permits to commute in/out of base and provide mom with support.
* Family was flagged as “combative” and treated “harshly”.
	+ Community Resource Coordinator met the patient and family at regional clinic appointment to provide support to parents and advocate with clinic staff. The team learned this parent was a first-time dad who was exhausted and frustrated with navigating referrals and services for his infant whom he felt was being looked over and kept from supports.

**Common themes of inequity across systems:**

* Lack of interpreters available for communicating prompt concerns.
* Complicated telephone tree leading to general voicemails.
* Unclear process for utilizing interpreter services.
* Delays in receiving call back.
* Handoffs to resources without interpretation services.
* Unclear when to use Medicaid Managed Care plan (MCO) interpreter.
* Lack of continuity across providers.
* Assure use of quality interpreter and translation services. Communicate parent needs ahead of time.
* Even with providers utilizing interpreters, families deserve to receive care in their primary language.
* Translation often relays literal words instead of meaning and intent.
* Assumption that provider’s beliefs (medicine, mental health, etc.) are correct and applicable to all children.
	+ Open communication and dialogue are needed.
* A person’s comfort level with sharing information is dependent on individual and cultural beliefs.
* Family roles and hierarchy of authority can vary between and across ethnically diverse families.
* Developmental milestones can differ widely across cultures.
* Social-emotional development and bonding can be complicated when parents are dealing with grief.
* Not all caregivers have villages or strong social supports, particularly newer immigrant families.

**Things to consider based on the observations of the Navigation Staff and the evaluative input from families:**

* More education for providers around perinatal mental health and parental grief.
	+ Families’ grief of having a child with special health care needs can feel like they are grieving a death of a child that “could have been”.
	+ Provider training to focus on perinatal mental health for depression, anxiety, grief, racial trauma, etc.
	+ Provider training to focus on postpartum depression.
* Continued provider training around acknowledging and examining one’s own culture or “norms” to eliminate bias and assumptions.
* Provider training around non-judgmental approach when interacting with families and avoiding overgeneralizations.
	+ Use of inclusive language.
	+ Consideration of what constitutes a “family”, “parent”, or “caregiver” including unique gender roles and roles of extended family members within a family’s culture.
	+ Taking the time to understand each family’s values and beliefs with the understanding of heterogeneity within a culture.
* Acknowledging institutional and systemic racism and ableism that families seek care in and trust with their child’s life.
	+ Equitable access to care for BIPOC (Black, Indigenous, People of Color) caregivers that includes extended appointment times for families needing interpretation.
	+ Communication via text for equitable healthcare access.
	+ Call organizations/referrals ahead of time to provide accurate step by step instructions to achieve warm handoffs.
	+ Ways to support caregivers who may have literacy challenges, low health literacy, or cognitive delay with dignity.
* Provider training around strengths-based approach.
	+ Always start and end with the child and family’s strengths.
	+ Incorporating family protective factors in treatment.
	+ Collaborate with families to honor their unique family values.
	+ Give information to families in ways that promote self-efficacy and autonomy.
	+ Engage in open dialogue and be open to new ideas or modifying the course of treatment.

The Birth to One team found that as they intentionally worked to meet family’s needs based on a family-centered care model that took into consideration a family’s culture and community, their family traditions, language, and their health literacy, that it was easier to create a “Road Map” whose foundation was centered around what they needed to be successful in the care of their child.