

Engaging Spanish-Speaking Families in Newborn Screening: Key Takeaways from Leaders in Hispanic Health

In April 2017, Baby's First Test convened leaders and health workers from local and national organizations serving Hispanic* communities in the Washington, D.C. metropolitan area. The meeting provided a forum to explore strategies to foster awareness-building and engagement with Latino and Spanish-speaking families in newborn screening.

Demographic Landscape: Latino Families & Children in the U.S.

As the Hispanic population rises, more Spanish-speaking families enter the public health and healthcare systems each year, including newborn screening programs. The benefits of newborn screening touch nearly all babies born in the United States, from coast to coast, spanning rural and metropolitan regions. As such, it is increasingly important to understand and factor in the unique experiences of Latino communities when educating and engaging them in the newborn screening process at the local, state, and national levels.

Latinos are the fastest-growing segment of the child population, occupying an increasing share of the 4 million babies born annually in the U.S. Between 2000 and 2015, the Latino youth population nearly doubled, and this trend is projected to extend into the coming decades. **In 2014, almost 25% (1 in 4) children were Hispanic, and as soon as 2035, that proportion will grow to 32% (just shy of 1 in 3).**¹

In 2016, UnidosUS, formerly known as the National Council of La Raza (NCLR), published a report depicting the current demographic landscape of Latinos in the U.S. and capturing trends in healthcare, citizenship, and language dominance, among others¹. The report paints a variegated and heterogeneous picture of the 53 million Latino U.S. inhabitants and highlights compelling data to negate the concept of a "standard" Latino family experience. For example, while "Hispanic" or "Latino" may connote "primarily Spanish-speaking", UnidosUS's findings suggest a different trend within the shifting and assimilating Latino population. In 2014, only 17% of Latino children under 18 lived in limited English-speaking households. Furthermore, just 6% of these children were first-generation U.S. residents.

Access to Healthcare & Insurance

Following the Affordable Care Act and gains in Medicaid and the Children's Health Insurance Program (CHIP), the percentage of the Hispanic child population that lacks health insurance has nearly decreased by half

between 2008 and 2014 (19% to 10%). Despite this substantial stride, expansion of coverage alone has not eliminated the health equity gap. **The data reveal that a majority of Hispanic children (63%) still lack access to high-quality care through a medical home compared to 34% of their non-Hispanic white counterparts.** Immigration status, parental education, poverty, and access to transportation can augment these persistent disparities¹. In the context of newborn screening, it becomes crucial to consider the factors impacting health when addressing the needs of Latino children who require follow-up clinical care after an out-of-range newborn screen or diagnosis.

SNAPSHOT OF LATINO CHILDREN IN THE U.S.

- In 2014, nearly 1 million of the 4 million babies born in the U.S. were Latino²
- 1 in 3 children will be Latino by 2035¹
- Nearly half of U.S.-born Latinos are 18 or younger³
- The 2014 birth rate for Hispanic women (2.1 births per woman) exceeded that of non-Hispanic white women (1.9) and non-Hispanic black women (1.8)¹
- 37% of Latino children ages 5-17 speak only English at home³
- Only 10% of Hispanic children were uninsured in 2014 (down from 19% in 2008), but access to reliable, quality healthcare remains a considerable issue¹

* Following the example of the U.S. Census Bureau and UnidosUS, the terms "Hispanic" and "Latino" are used interchangeably throughout this brief and refer to people of Mexican, Caribbean, Spanish, Central and South American, or other Hispanic descent; they may be of any race.

Baby's First Test's Engagement with Spanish-Speaking Families

Baby's First Test houses the nation's newborn screening clearinghouse. Launched in 2011, the Clearinghouse is supported and funded as a result of the Newborn Screening Saves Lives Act of 2008. The program and its website BabysFirstTest.org promote awareness, knowledge, and understanding of newborn screening at the local, state, and national levels. Baby's First Test is dedicated to providing support and education through the newborn screening experience for parents, family members, health professionals, and the public at large.

The demand by clinicians, state programs, and other educators for multilingual newborn screening resources prompted the launch of Spanish.BabysFirstTest.org in 2015 and Spanish translations of additional educational resources in 2016. To build upon this foundation, the Clearinghouse received supplemental funding to gather input from the Spanish-speaking community, with the aims of 1) effectively reaching families and connecting them to newborn screening information, and 2) updating Spanish-language materials (e.g. website, infographics) to better meet the needs of the target audience.

Activities supported by this funding included participation at the 2017 National Council of La Raza Health Summit in Phoenix and conducting focus groups at a D.C.-area federally qualified health center. These activities followed a community meeting in April that kickstarted partnership building.

For more information and resources, please visit:
BabysFirstTest.org
Spanish.BabysFirstTest.org

References

- 1 Mark Mather and Patricia Foxen. "Toward a More Equitable Future: The Trends and Challenges Facing America's Latino Children" (Washington, DC: National Council of La Raza, 2016), http://publications.nclr.org/bitstream/handle/123456789/1627/towardamoreequitablefuture_92916.pdf (accessed July 2017)
- 2 Brady E. Hamilton, Joyce A. Martin, and Michelle J.K. Osterman. "National Vital Statistics Reports" (Atlanta, GA: Centers for Disease Control and Prevention, 2016). Vol. 65, no. 3, pp. 8-11. http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_03.pdf (accessed September 2017)
- 3 Eileen Patten. "The Nation's Latino Population Is Defined By Its Youth" (Washington, DC: Pew Research Center, 2016), <http://www.pewhispanic.org/2016/04/20/the-nations-latino-population-is-defined-by-its-youth/> (accessed September 2017)
- 4 Anna Brown, Gustavo López, and Mark Hugo Lopez. "Digital Divide Narrows for Latinos as More Spanish Speakers and Immigrants Go Online" (Washington, DC: Pew Research Center, 2016), <http://www.pewhispanic.org/2016/07/20/digital-divide-narrows-for-latinos-as-more-spanish-speakers-and-immigrants-go-online/> (accessed August 2017)



Community Leaders Meeting

Baby's First Test extended an invitation to community stakeholders from organizations with significant expertise and knowledge in engaging Hispanic families in health settings. The meeting on April 24, 2017 was structured as an open discussion to facilitate sharing of ideas and action steps.

Participating Organizations

- [Baby's First Test](http://BabysFirstTest.org)
- [La Clínica del Pueblo](http://LaClínicaDelPueblo.org)
- [Family Voices](http://FamilyVoices.org)
- [Mary's Center](http://MarysCenter.org)

Meeting Outcomes: Identified System-Level Engagement Needs

1. A people-centered, culturally sensitive engagement strategy that meets families where they are, taking into account possible barriers such as access to care via a medical home, low health literacy, limited familiarity with the healthcare system, and degree of acculturation
2. Buy-in and willingness from providers to engage with patients compassionately, supported by education and training opportunities in culturally responsive care
3. Education for families on the specifics of newborn screening as well as how to be self-advocates in the health system more broadly
4. Robust reciprocal partnerships between the Clearinghouse and local clinics, health centers, national organizations, professional societies, and advocacy and family services groups

Crafting an Engagement Plan: Recommendations to the Clearinghouse

- Many of our current engagement approaches can apply to our outreach efforts. Consider that Spanish speakers want the same information for their families that English speakers do, but **the ways in which we communicate that information may be radically different.**
- Circulate Baby's First Test resources through online forums and social media to reach the **large number of Hispanics finding health information on the internet**⁴. Furthermore, because many families still use **word of mouth as a potent means of communication**, information found online can be spread within social circles via conversation.
- At the local level, **rely on the leadership at community centers** that have established trust with their patients for guidance on how best to integrate newborn screening education into existing frameworks.
- There are unifying cultural values that span Hispanic communities. However, it's important for the Clearinghouse to recognize the **heterogeneity of the Hispanic population** and the culturally-informed educational needs of distinct subgroups.
- **Engage family and community members in the education process.** In this engagement, identify who is the key decision-maker in the family and/or community and to what extent this is culturally influenced.
- To disseminate information and resources, **partner with federal agencies and national organizations** with established networks and experience working in Hispanic communities.