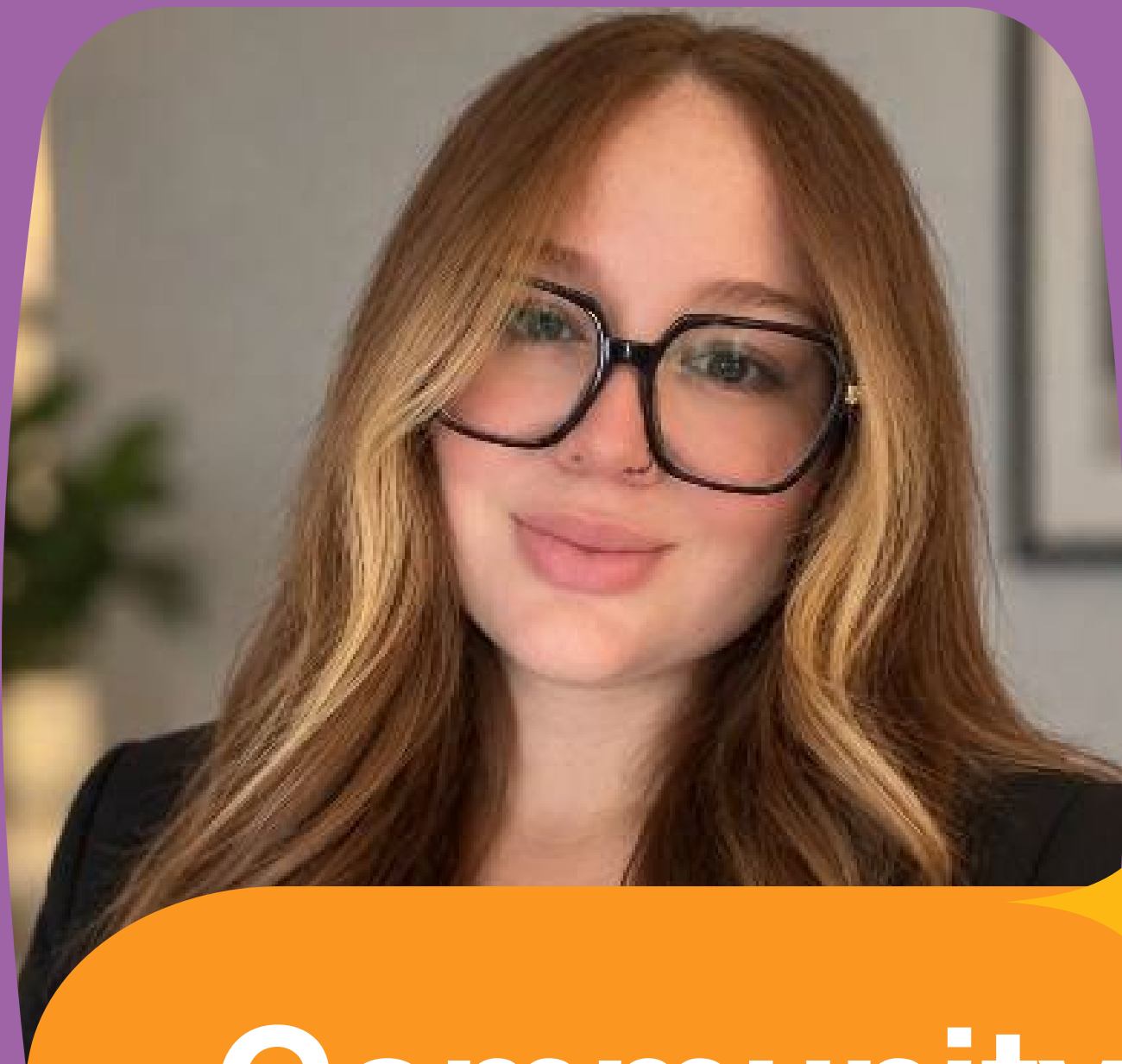
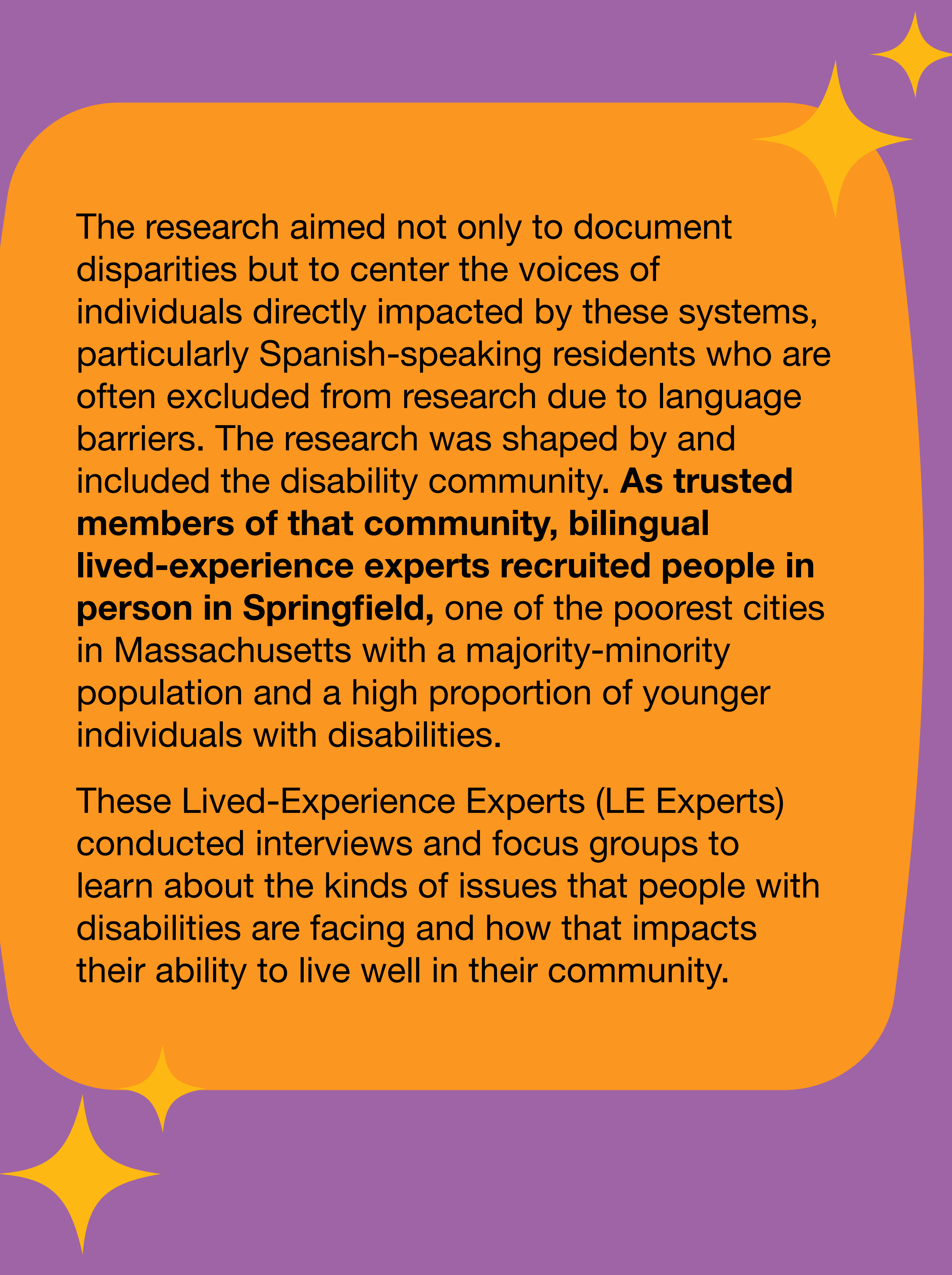


Advancing Equity through Home and Community- Based Services



Community Leading the Way

The Disability Policy Consortium, a disability rights organization, set out to explore **inequities in access to Home and Community-Based Services (HCBS) among Latinx and Black/African American populations with disabilities in Springfield, Massachusetts**, including whether disparities in HCBS access contribute to increased institutionalization among communities of color. HCBS services are critical to enabling people with complex disabilities to live in their community and preserve their independence, dignity, and health.



The research aimed not only to document disparities but to center the voices of individuals directly impacted by these systems, particularly Spanish-speaking residents who are often excluded from research due to language barriers. The research was shaped by and included the disability community. **As trusted members of that community, bilingual lived-experience experts recruited people in person in Springfield,** one of the poorest cities in Massachusetts with a majority-minority population and a high proportion of younger individuals with disabilities.

These Lived-Experience Experts (LE Experts) conducted interviews and focus groups to learn about the kinds of issues that people with disabilities are facing and how that impacts their ability to live well in their community.



What Did This Research Reveal?

Latinx and Black populations experience high levels of negative social determinants of health, related to poverty and housing status, which intersects with their access to home and community-based services. Community members expressed a mix of risk and resiliency factors, with some experiencing social isolation and others having strong family connections. Additionally, some individuals had an understanding of the services available to them, while others did not, **preventing them from living meaningful, independent lives in the community of their choice.**

Recruitment challenges in the research were pronounced, particularly within the Latinx community. A climate of fear related to immigration enforcement contributed to hesitancy in participating in research.



Why Do These Findings Matter?

As federal funding for home and community-based services is threatened, the lives of people with disabilities will be fundamentally impacted, affecting where and how they live and their overall quality of life.

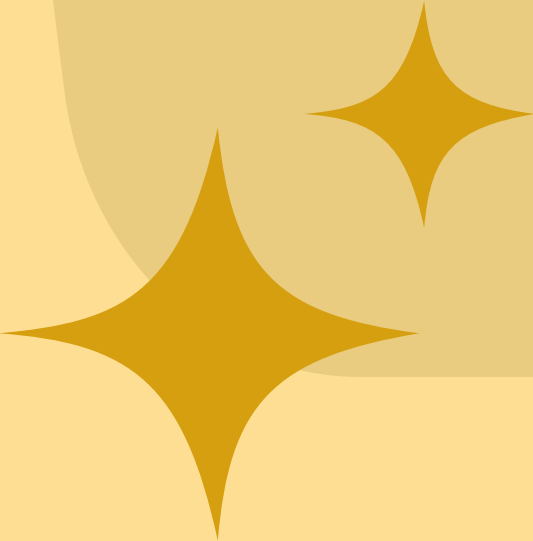
In response to recruitment challenges that emerged during the study, the research team **strengthened screening protocols, expanded community outreach through local partnerships, and integrated lived experience experts—**particularly Spanish-speaking community members—to improve trust and engagement.



“One of the biggest things I have learned [from this research] is how many struggles people with disabilities face that may not always be visible to others. **Transportation, access to services, finding reliable personal care assistance, maintaining independence, and the fear of having to move into a nursing home are just some of the concerns people shared...**

This project also reminded me of the importance of listening. Everyone has their own story, and sometimes the most meaningful thing we can do is create a safe space for people to share their experiences. I am leaving this project with a greater appreciation for advocacy, community involvement, and the importance of making sure people with disabilities have a voice in decisions that affect their lives.”

*–Lyanne Ortiz,
lived experience expert*





How the Research is Shaping the Future

Community feedback informed revisions to recruitment materials, making them more accessible and culturally relevant. These adaptations reflect a shift toward more flexible, community-centered research practices. Future efforts should **center community relationships, adapt research design to real-world contexts, and ensure adequate resources for sustained engagement.** These lessons contribute to strengthening participatory research as a tool for systems change.

This research study represents one of the first of this magnitude to be led by an organization that is run by people with disabilities, and it **has energized and empowered people who have engaged in the research process,** particularly lived experience experts who played a central role in developing research guides and carrying out the research, all while building their own research skills.



Learn More

AcademyHealth supports community-led researchers producing evidence for community-driven solutions. Learn more about all Community Research for Health Equity grantees at:

www.academyhealth.org/CRHE