



## Lived Experience: The Practice of Engagement in Policy

By Laura Hogan, Allison Gertel-Rosenberg, Georgia Thompson, and Debbie Chang

## INTRODUCTION

Health care transformation efforts are accelerating, bringing a heightened focus on policy and practice changes to promote optimal health and deliver maximum value. Elevating value and well-being in health systems is raising the bar on meaningful outcomes and this, in turn, is incentivizing health systems' greater attention to social determinants of health and community environments. As health systems engage to realize a coordinated experience in health care as well as address the underlying conditions that influence health, multi-sector collaboratives and integrators are gaining momentum as best practices to link clinical care, social services, and community health strategies.

Multi-sector collaborations offer an opportunity to link and align efforts that address the full continuum of immediate needs and ensure attention to upstream strategies for optimal population health outcomes across the life span. Working across sectors to coordinate services relies on one or more entities to serve as a population health integrator and carry out integrative functions to support collective impact. Aligning outcomes, setting joint priorities, sharing data, and engaging community require the skillful support of integrators.

An emerging core tenet of effective collaboration to improve systems and services is the authentic engagement of community residents with lived experience alongside health and social service organizations to co-design policy and practice and address equity. In fact, there is growing evidence that successful system change requires engagement and leadership of individuals with lived experience.

As collaborative groups build trust and transparency between organizational members and community participants, questions about effective practice emerge.<sup>1, 2, 3, 4</sup>

- How do we create structures and processes to support all stakeholders as equal partners in voice and power to design outcomes, strategies, and accountabilities?
- How do we align priorities so that policy and system changes reflect the voice of lived experience?
- How do we connect local context and lessons to state policy to inform more effective financing, service delivery, and accountability?

This issue brief compiles the wisdom of interviewed state and community leaders who are forging effective practice to address these questions through Harnessing Opportunity for Positive, Equitable Early Childhood Development (Project HOPE, see page 4) and other multi-sector partnerships. They are testing, reflecting, and sharing their experiences to inform our collective learning. This brief synthesizes the thought leadership of community organizers, parents, public sector, and organizational leaders committed to bringing the voice of experience to policy and practice decisions.

### Values and Language

**This issue brief highlights the value of ensuring the involvement of those with lived experience in policy and systems change. The philosophy embedded in the language "lived experience" is that firsthand knowledge gained from actual participation in a program, system, neighborhood or population group is an important refinement to community engagement practice.**

**Community engagement spans a continuum of activities – from focus groups to participation in governance. For this brief, community engagement refers to involving residents who live, work, and learn in a community in the design, planning, and decisions for their community. As referenced above, lived experience further refines this to ensure that engagement includes those experiencing the systems, and services discussed.**

<sup>1</sup> The experience of community engagement for individuals: a rapid review of evidence; Pamela Attree, Beverly French, Beth Milton, Susan Povall, Margaret Whitehead, Jennie Popay; <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1365-2524.2010.00976.x>

<sup>2</sup> Community Engagement Matters (Now More Than Ever); Melody Barnes and Paul Schmitz; [https://ssir.org/articles/entry/community\\_engagement\\_matters\\_now\\_more\\_than\\_ever](https://ssir.org/articles/entry/community_engagement_matters_now_more_than_ever)

<sup>3</sup> Community engagement, A key strategy for improving outcomes for Australian families; CFCA Paper No. 39 – April 2016; <https://aifs.gov.au/cfca/publications/community-engagement/why-community-engagement-important>

<sup>4</sup> Vital Village [Networks of Opportunity for Child Wellbeing \(NOW\)](https://www.networksofopportunity.org/bright-spots), an initiative of the Vital Village Network at Boston Medical Center, was launched in 2016 with support from the Robert Wood Johnson Foundation and led a strategic planning process to design a robust infrastructure to support the development of networks of opportunity across prenatal through early childhood systems for optimal well-being. <https://www.networksofopportunity.org/bright-spots>

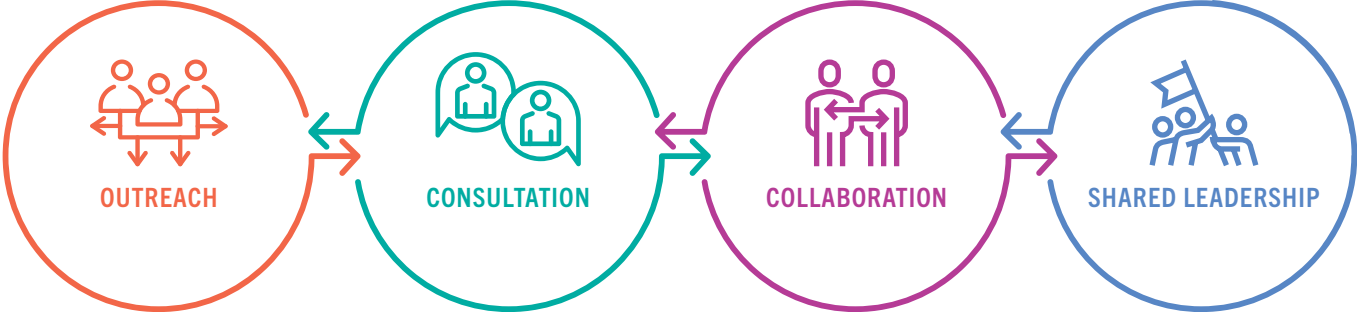
# THE PRACTICE OF ENGAGING INDIVIDUALS WITH LIVED EXPERIENCE

Effective community engagement is not yet common practice in health systems or early childhood sectors. Therefore, even where willingness and readiness to engage individuals with lived experience exists, systems are challenged to effectively navigate roles, language, practices, and power dynamics.

A literature review and interviews with activists document a growing consensus about a menu of community engagement activities and how they can support better programs and improved systems. Interviewees are quick to point out that a set of activities without the core values and infrastructure to advance the leadership of residents with lived experience will fall short of success.

Establishing a common language and articulating the value of policy design and decisions by those holding knowledge of its impact are an essential part of the pathway to productive change efforts. Moreover, adopting the full range of practices for engagement is critical. The Race to Justice Community Engagement Framework offers this rubric of options:<sup>5</sup>

Policy Link notes, “Community engagement is not just a set of activities and methods confined to a particular project, policy, or process. Rather, it is a way of communication, decision-making, and governance that recognizes community members’ power and includes them and other stakeholders in identifying problems and making decisions that promote equitable outcomes. Public agencies have plenty of tools for basic public participation and protocols for using them, but many of these are ineffective because they do not address the legacy challenges in low-income communities and communities of color, nor do they tap into their expertise and organizing capacity. Community engagement encompasses a more comprehensive approach, creating practices and institutionalized mechanisms that prioritize the interests of marginalized communities and facilitate interactions between agency staff and diverse stakeholders.”  
*The Race to Justice Community Engagement Framework, New York Department of Health and Mental Hygiene*







Using this rubric, the table (on page 3) offers examples from projects and interviews about how and when each community engagement practice can be employed to bring lived experience into design and decision-making. While every activity is useful, community engagement too often relies solely on outreach and consultation that

is designed and carried out by organizational partners. Leaders in the field reflected that current practice generally retains organizations and systems in leadership and decision-making roles. The participation of individuals with lived experience in the design of policy and ongoing membership in leadership and governance teams is less frequent.

<sup>5</sup> Race to Justice Community Engagement Framework from New York City Department of Health and Mental Hygiene, May 2017. <https://www1.nyc.gov/assets/doh/downloads/pdf/che/community-engagement-framework.pdf>

## COMMUNITY ENGAGEMENT ACTIVITIES AND LIVED EXPERIENCE

Engagement Strategy	Activities	Considerations for Inclusion of Lived Experience
 <p><b>OUTREACH</b></p>	<p>Town hall meetings, email blasts, canvassing, door knocking</p>	<p>Target outreach to participants of the sectors, programs, and systems under consideration with appropriate attention to confidentiality.</p>
 <p><b>CONSULTATION</b></p>	<p>Input via interviews, surveys, focus groups, or online platform</p> <p>Reviewing plans and priorities developed by organizations</p> <p>Gathering stories to narrate the experience of residents/ participants and consider them actionable research</p>	<p>Conduct interviews and group sessions specifically with participants with lived experience.</p> <p>Include questions to gather input directly from individuals with lived experience pertaining to the needs or services and systems.</p> <p>Build community capacity through methods such as Community-Based Participatory Research.<sup>6</sup></p>
 <p><b>COLLABORATION</b></p>	<p>Design process or community sessions to develop plans and improve services</p>	<p>Organizational representatives work alongside individuals with lived experience in design sessions to develop and then prioritize strategies through collaborative practice.</p>
 <p><b>SHARED LEADERSHIP</b></p>	<p>Participating with equal voice in program services, policy decisions, and systems improvements</p>	<p>Ensure that individuals with lived experience are part of leadership teams and governance structures and that lived experience is a stated qualification.</p> <p>Ensure training and resources are available to support active participation.</p>

Moving beyond traditional practices of outreach and consultation to resident-led and resident-driven design, priority setting, decisions, and governance is the emerging frontier for practice. As the experience and effective practice of community engagement spreads and deepens, examples are emerging that incorporate the full continuum. Moreover, communities are forging practices that advance beyond residents’ input to programs and services to incorporate lived experience in policy development and decisions. For example, organizations and initiatives often seek community input through surveys or town hall sessions to identify and overcome barriers to programs or improve service delivery. Emerging practices include lived experience participants at state policy stakeholder councils, the governance table, or adopting methods like participatory budgeting (a process of community residents deciding how public resources might be used).<sup>7</sup>

The following principles for effective practice synthesize input from interviews and literature. It is evolving practice continuing to be informed by a growing number of community engagement initiatives.

### BRINGING LIVED EXPERIENCE INTO POLICY

Community leaders across the country are embracing activities to ensure the voice of lived experience in policy and practice design. The following section highlights experiences from Project HOPE grantees in Florida, New Jersey, Oklahoma, and Washington<sup>8</sup> and other community organizations. They offer examples of the “how and why” about what is needed to adopt and succeed with ongoing engagement by *outreaching, consulting, collaborating, and sharing leadership*. Successful engagement requires support from community integrators to recruit, train, and facilitate participation of individuals with lived experience.

<sup>6</sup> Wallerstein, Nina B., and Bonnie Duran. “Using Community-Based Participatory Research to Address Health Disparities.” *Health Promotion Practice* 7, no. 3 (July 2006): 312–23.

<sup>7</sup> Participatory Budgeting Project. Accessed September 1, 2019. <https://www.participatorybudgeting.org/what-is-pb/>

<sup>8</sup> “Nemours Project HOPE.” *Moving Health Care Upstream*. Nemours Children’s Health System. Accessed September 1, 2019. <https://www.movinghealthcareupstream.org/nemours-project-hope/>

## Principles for Community Engagement

- Participants with lived experience are experts.
- Goals, outcomes, policy, and practices for health, education, and human service sectors are transparent and co-designed, with participants with lived experience and organizational leaders working together.
- Accountability and commitment to equity are measured.
- Inclusive participation is supported with resources and accessible to all members of the community.
- An asset-based mindset, rather than deficit-based, and the stamina to keep improving are the foundation of engagement.
- A culture where everyone is open to new opinions, values diversity, and practices humility is embraced.
- Sustained relationships and trusting partnerships are nurtured through consistent communication and involvement.
- There is shared decision-making and a balance of power between those with lived experience and organizations in developing community-driven and co-designed programs and policies.

## Outreach to build trust and learn from stories

Project HOPE Oklahoma is reaching out to document the stories of families and cultivate community, in particular among tribal members and Head Start parents to understand barriers (structural or financial) and implicit biases that contribute to inequities. With data in hand about significant disparities in infant mortality, they knew that they needed community and family context to understand how to lower infant mortality for all, attend holistically to families, and achieve equity in communities. They began with the statement, “Tell us about a time when you were able, (or not able) to overcome barriers during pregnancy, birth or in the first year of your child’s life.” Through outreach to families, they are gathering the full story behind the data and taking time to build trust and develop parent capacity to participate actively at the state level.

*We employ a range of respectful practices to support parent engagement. We offer equity training to parents. We use interpreters, offer child care, provide travel and gift cards as a stipend. – PROJECT HOPE OKLAHOMA*

## Project HOPE supports initiatives in four states

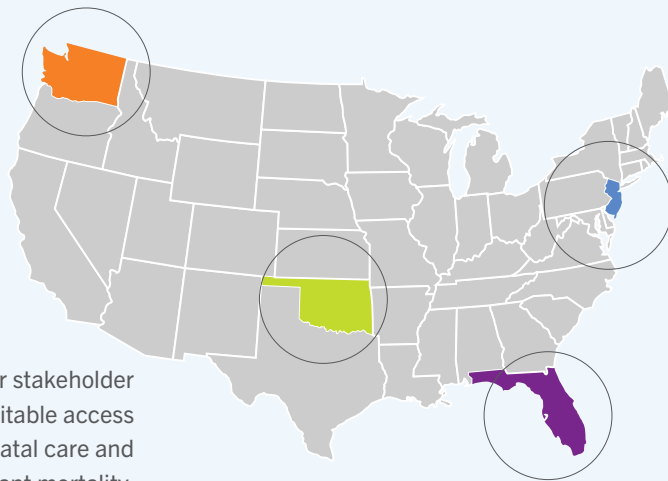
Funded by the Robert Wood Johnson Foundation, the Harnessing Opportunity for Positive, Equitable Early Childhood Development Project (Project HOPE) ensures equitable access to health services and healthy development opportunities for children under five and their families by partnering with states and local organizations on policies and programs that result in systems change.

Examples of these services and resources are reflected in the current areas of focus for Project HOPE states listed below.

In addition to funding to support these efforts, Nemours grantees receive technical assistance, tools, and support through Nemours and national partners, Altarum, Boston Medical Center’s Vital Village Network, and the Institute for Public Health Innovation.

In **Washington**, an integration workgroup is expanding equitable access to health, development, and social services through a centralized-access model called Help Me Grow.

In **Oklahoma**, a cross-sector stakeholder group is expanding equitable access to high-quality prenatal care and resources to address infant mortality.



In **New Jersey**, stakeholder organizations are working to identify a path to more equitable access to quality health and child care services.

In **Florida**, a coalition is building on efforts to increase equitable access to developmental screenings and early intervention that promote social-emotional development.

## Consultation to Inform Priorities

Project HOPE New Jersey conducted focus groups in two communities to understand how programs and services impact families. Organized in a local church, state staff first heard from a group, ranging from teens to great-grandmothers, about their experiences of pregnancy and early childhood services and systems. It was clear that the experiences had not varied much over decades of time. This impactful input led to multiple trips where state staff engaged in a fruitful exchange to inform needs assessments, gather improvement recommendations, and vet specific proposals. Looking ahead, they hope to institutionalize ongoing feedback loops through parent-led councils across the state.

Project HOPE Washington partners with Washington Communities for Children, a statewide network of 10 regional coalitions dedicated to improving the well-being of children, families, and communities. Sharing a joint mission, goals and guiding framework, each coalition is community-grown and self-governed. When the Washington State Department of Children, Youth, and Families (DCYF) wanted to gather input for a federal Preschool Development Grant needs assessment, the coalitions were able to mobilize rapidly to host 100 sessions resulting in 1,000 responses from families and organizations through the structure of Washington Communities for Children. In the Project HOPE Central Washington community of Yakima, 50 percent of the sessions were conducted in Spanish. They mobilized quickly and ensured candid input by asking English as a Second Language teachers to incorporate the consultation session directly into classes. DCYF is currently analyzing the data to lift up themes identified by families and take the results back to communities. The information will be used across multiple agencies and departments to guide services and policy. In addition, the Central Washington coalition is using this local resident input to help design the Help Me Grow<sup>9</sup> system of resources and referral, coordinated access points, connections to health care, and data systems.

*It has to be local and connected to state; that requires resources and a commitment to listen. Community-driven early learning coalitions are beginning to self-organize and connect to share learning. Now, coalitions speak for themselves at the state level. There can be tension in the process, but what is exciting is to see enough engagement and trust to figure it out, enough transparency to hold each other accountable.*

– PROJECT HOPE WASHINGTON

## Collaboration for ongoing improvement

Project HOPE Florida, in partnership with Vital Village,<sup>10</sup> and organizations and families in the Parramore Heritage community, conducted a Community-Based Action Lab. There was passion — from organizations and residents alike — to enhance the community for children and look to the community to lead the action planning. Equitable access to services was a key theme and priority. At the meeting, parents spoke up about what gaps exist in family supports, what local priorities should be, and what system changes are needed. These gaps included, for example, that 211 referrals are not localized to neighborhoods and a recent school/clinic co-location is not achieving its goals because of restrictions based on insurance coverage. The state cross-sector group is committed to integrating locally developed priorities into its three- to five-year state action plan and supporting local follow up.

*It takes intentional support for residents to have an equal voice and full participation with organizational representatives in planning and system improvement. State agencies now see family voice as a form of equity – bringing parents to the table and compensating them for their time. We follow an internal practice of inviting both residents and state-level stakeholders to develop shared vision and strategic priorities. Trained and experienced parent leaders become effective coaches for other parents so we can expand participation and elevate the voices of leaders with lived experience.*

– PROJECT HOPE FLORIDA

First 5 Los Angeles invests in Best Start Networks in 14 geographic areas that have faced historic disenfranchisement and oppression yet remain communities of great strength and resiliency. Working in partnership with families and communities helps shape and inform First 5 Los Angeles' advocacy work at county, state, and federal levels. First 5 funding provides the platform for parents and communities to realize and exercise their power to effectively drive and contribute to policies that impact families and neighborhoods. As a California Assembly member commented, “We hear a lot from polished lobbyists in Sacramento, but there is something especially moving when you hear from young people advocating for themselves, telling their own real-life stories in the hope that what they have gone through will have a positive impact on other people.”

<sup>9</sup> Help Me Grow is not a stand-alone program, but rather a system model that utilizes and builds on existing resources in order to develop and enhance a comprehensive approach to early childhood system-building in any given community. Successful implementation of the Help Me Grow model requires communities to identify existing resources, think creatively about how to make the most of existing opportunities, and build a coalition to work collaboratively toward a shared agenda. <https://helpmegrownational.org/hmg-system-model>

<sup>10</sup> Vital Village <https://www.vitalvillage.org/>

## Shared Leadership at the governance table

The Magnolia Place Community Initiative<sup>11</sup> (MCI) is an effort to transform an entire community by uniting the residents and public and private organizations to change how both residents and organizations think and act with the ultimate goal of improving outcomes for an entire community of vulnerable, low-income children in Los Angeles. MCI is building on previous work to elevate the influence of lived experience in decision-making by launching a Learning Academy to support resident leadership capacity, encourage the placement of residents on nonprofit boards and neighborhood councils, offer tools to organizations for integrating resident leader board members, and ongoing mentorship through an Alumni Network. The city of Los Angeles is a design partner in the Academy with the goal of seeing more residents elected to the 100 Neighborhood Councils across the city. Neighborhood Councils receive a budget annually to support community improvement projects and MCI hopes to see greater investments in schools, parks, and other resident priorities by changing the Neighborhood Council representation from predominantly business leaders to residents.

Believing all individuals have the agency, potential, and voice to shift power from institutions back into the hands of the community, SOMOS Mayfair works to uplift the very people most affected by disparities to take action, create meaningful connections with their peers, and make an impact in the Mayfair neighborhood that supports their families' immediate needs and future prosperity. In the past three years, SOMOS has focused efforts on two long-term community priorities: fostering early school success and nurturing family wellness.

*Across four different schools, we support parents in thinking about what quality education looks like, getting involved in opportunities to support their students' learning, and addressing immediate gaps through community-led solutions and programming. We were ready with parents organized to take action when a school board member wanted to use school safety funding for bullet proof vests. Parents showed up to*

*successfully change that. – SOMOS MAYFAIR*

## CONCLUSION

Community engagement practice to alter the balance of power and bring equal voice and participation of communities' lived experience to the design and implementation of policy is evolving and becoming rooted in community initiatives. Early adopters are forging ahead with a refreshing willingness to reflect on their journey as it unfolds and share practices to build more effective systems. As leaders highlighted throughout this issue brief, engagement centers on the values, the processes, and the people.

To accelerate and sustain their efforts, funders and policymakers should consider:

- Providing specific and ongoing funding for integrator functions to organize leadership development for both community and organizational leaders in support of shared power and sustainability.
- Normalizing policy, practices, and specific funding allocations to provide flexible, easily accessed resources for robust participation of leaders with lived experience.
- Documenting and communicating the practice and impact of community-led policy.
- Adapting statewide policy to incorporate flexibility that responds to local context, history, and culture.
- Supporting accountability for community systems and policies to incorporate the voice of lived experience in policymaking.
- Requiring community-driven collaboration as part of system improvement initiatives and regulatory updates.

---

<sup>11</sup>Magnolia Community Initiative (MCI) is a network of 70 partner organizations in Los Angeles with shared goals for the 35,000 children living in a 500-block area of nurturing parents, good health, financial stability, and educational success. Residents are actively engaged in the design and success of the Initiative as content experts. <http://magnoliaplacela.org>

## APPENDIX

### Featured Projects

Project HOPE Florida has aligned with the Early Childhood Comprehensive Systems (ECCS) Impact Project to improve child health outcomes and kindergarten readiness by increasing developmental screening and promoting social-emotional development in young children. Florida ECCS is led by the **Florida Association of Healthy Start Coalitions** (FAHSC) and is primarily funded by the Health Resource & Services Administration (HRSA). Florida is one of 12 states participating in the national ECCS Collaborative Improvement and Innovation Network (CoIIN) to improve early childhood systems, resources, and coordination across sectors. Project HOPE is aligned with this companion effort and leverages its resources, such as its state advisory group, which is comprised of state and community-level stakeholders. Project HOPE builds upon previous efforts to promote equity and reduce disparities among young children through a partnership with Parramore Kidz Zone (PKZ) in Orlando. PKZ is a place-based initiative in Parramore Heritage, Orlando's highest poverty neighborhood with the mission to level the playing field for Parramore's children, equipping them to become successful, healthy, well-educated adults.

<https://www.movinghealthcareupstream.org/increasing-developmental-screening-and-promoting-social-emotional-development-in-florida>

The New Jersey **Interdepartmental Planning Group** (IPG), consisting of the administrators from each of the state's departments with oversight of programs and services for children from pregnancy to age 8, is the Project HOPE New Jersey state-level cross-sector team. The IPG is engaging locally in Bridgeton and Atlantic City to learn from communities about their experiences with state-funded services and build feedback loops. The IPG has been analyzing the qualitative data collected during these community visits along with state and local quantitative data to identify opportunities to improve policies and practices to increase access to programs or services and to build local capacity to better support and advocate for children and families. Project HOPE is also working locally with the Essex County Council for Young Children (ECCYC), one of 21 county councils statewide. Its goal is to strengthen collaboration between parents and community stakeholders focusing on health, early care and education, and safety.

<https://www.movinghealthcareupstream.org/project-hope-consortium-shared-geography-new-jersey>

The **Oklahoma Partnership for School Readiness** formed an Early Learning Equity and Diversity (E-LEaD) Team to work toward a more equitable system of early care and education. This team works to advance the vision that every child, regardless of race, ethnicity, or family income, has the best opportunity to achieve optimal health and well-being. Infant mortality has been selected as a focus for Project HOPE in Oklahoma because it represents a measure of overall health of a community and is unfortunately an indicator in the state in which significant disparities exist. The Oklahoma Partnership for School Readiness is a long-standing public-private statewide partnership with 32 members. They provide critical integrator functions and rely on an evidence-based systems change framework that combines Systemic Learning Action Teams + Simple Rules and Small Wins Efforts to engage parents alongside organizations.

<https://www.movinghealthcareupstream.org/addressing-disproportionate-infant-mortality-in-oklahoma>

The **Washington State Department of Health** is the lead for Project HOPE in collaboration with other state-level and regional coalition partners. To align its efforts with the Essentials for Childhood Steering Committee, key state agencies, statewide partners, and community-driven priorities, Washington Project HOPE adopted the Help Me Grow (HMG) framework as a promising model for scaling statewide to address inequity. Help Me Grow is a model that works to promote collaboration across child-serving sectors to build a more efficient and effective system for optimal healthy development of young children. There are 10 regional early learning coalitions across Washington state. Two counties currently have funding to help implement HMG, seeking to connect state, community, and family input, and increase community voice in systems development. Now, Project HOPE funding offers an opportunity to support a third community in central Washington to surface lessons about how the state can best support local efforts and boost family perspectives, particularly in a rural area.

<https://www.movinghealthcareupstream.org/scaling-a-promising-model-statewide-to-address-inequities-in-washington-state>



**Magnolia Community Initiative (MCI)** is a network of 70 partner organizations in Los Angeles with shared goals for the 35,000 children living in a 500-block area of nurturing parents, good health, financial stability, and educational success. Residents are actively engaged in the design and success of the Initiative as content experts. MCI offers an organizational fellowship for staff to learn about authentic community engagement that challenges biases about resident engagement to move beyond transactional relationships. <http://magnoliaplacela.org>

**SOMOS Mayfair** was founded in 1997 (originally as the Mayfair Improvement Initiative) to address chronic crisis in Mayfair, a working-poor and immigrant neighborhood in East San Jose. In the early years, SOMOS partnered with government, corporate, and nonprofit allies to renovate community infrastructure, catalyze new community investment, and develop new coalitions. Over the years, SOMOS revamped itself to most effectively operate in line with the needs of the community and opportunities for regional partnerships evolved. In the past three years, this has led SOMOS to focus efforts on two long-term community priorities – fostering early school success and nurturing family wellness. <https://www.somosmayfair.org/about>

## Featured Resources

**Boston Medical Center's Vital Village Network:**

<https://www.vitalvillage.org> and <https://www.networksofopportunity.org/bright-spots>

**Race to Justice NYC community engagement framework:**

<https://www1.nyc.gov/assets/doh/downloads/pdf/che/community-engagement-framework.pdf>

**SOMOS Mayfair: Community Engagement Philosophy:**

<https://static1.squarespace.com/static/59c2ef99e5dd5b9e02e383e7/t/5cd09edbf9619a8727e03e5e/1557176027639/SOMOS+Community+Engagement+Philosophy.pdf>

**ReThink Health:** Pedja Stojicic, Blog hosted a [four-part series](#) exploring resident engagement for health system transformation; Resident Engagement Typology; Companion on Community Member Engagement for Health Action Chapters, Sonoma Health Action developed in partnership with ReThink Health:

- a. [https://www.rethinkhealth.org/wp-content/uploads/2018/02/RTH-ResidentTypologyOutcome\\_2152018.pdf](https://www.rethinkhealth.org/wp-content/uploads/2018/02/RTH-ResidentTypologyOutcome_2152018.pdf)
- b. <https://www.rethinkhealth.org/the-rethinkers-blog/exploring-resident-engagement-for-health-system-transformation>
- c. [https://www.rethinkhealth.org/wp-content/uploads/2018/02/RTH-ResidentTypologyOutcome\\_2152018.pdf](https://www.rethinkhealth.org/wp-content/uploads/2018/02/RTH-ResidentTypologyOutcome_2152018.pdf)
- d. <https://www.caponoma.org/wp-content/uploads/2020/01/2-HAC-RE-Companion-v3.0.1-1.pdf>

**Institute for Public Health Innovation:**

<https://www.institutephi.org>

**Tamarack Institute:**

<http://www.tamarackcommunity.ca/citiesdeepeningcommunity>

[https://cdn2.hubspot.net/hubfs/316071/Resources/Article/Tamarack\\_Articles\\_The\\_New\\_Civic\\_Leadership.pdf](https://cdn2.hubspot.net/hubfs/316071/Resources/Article/Tamarack_Articles_The_New_Civic_Leadership.pdf)

**PolicyLink:**

- a. <https://www.policylink.org/find-resources/library/strategic-ways-to-engage-the-community>
- b. <https://www.policylink.org/resources-tools/community-engagement-guide-for-sustainable-communities>
- c. <https://www.policylink.org/find-resources/library/developing-leadership-capacity>
- d. <https://www.policylink.org/find-resources/library/community-engagement>

**Community Engagement Toolkit:**

<https://www.collectiveimpactforum.org/sites/default/files/Community%20Engagement%20Toolkit.pdf>

**Center for Consumer Engagement in Health Innovation, Community Catalyst:**

- a. [https://www.healthinnovation.org/resources/publications/body/IMPACT\\_How-Consumers-Have-Shaped-Health-Delivery-Reform\\_FINAL.pdf](https://www.healthinnovation.org/resources/publications/body/IMPACT_How-Consumers-Have-Shaped-Health-Delivery-Reform_FINAL.pdf)
- b. <https://www.healthinnovation.org/work/building-advocacy-capacity>
- c. <https://www.communitycatalyst.org/resources/publications/document/Consumer-Policy-Platform-for-HST-web.pdf>
- d. <https://www.healthinnovation.org/work/stories>

**Prevention Institute: Community Engagement in Design and Planning:**

<https://www.preventioninstitute.org/sites/default/files/publications/Community%20Engagement%20in%20Design%20and%20Planning%20-%20Making%20Healthy%20Places.pdf>

**First 5 Los Angeles Best Start:**

<https://www.first5la.org/engaged-communities>

**Reflections on Community Organizing and Resident Engagement in the Rebuilding Communities Initiative**

**The Annie E. Casey Foundation:**

[http://www.lisc.org/media/filer\\_public/f3/c8/f3c8f82c-7d1e-4121-a988-f33d8893f5f5/08102018\\_resource\\_annie\\_casey\\_reflections.pdf](http://www.lisc.org/media/filer_public/f3/c8/f3c8f82c-7d1e-4121-a988-f33d8893f5f5/08102018_resource_annie_casey_reflections.pdf)

**Suggested Citation:**

**Nemours Children’s Health System,  
Nemours National Office of Policy & Prevention.  
Lived Experience: The Practice of Engagement in Policy.  
www.movinghealthcareupstream.org  
Published April, 2020. Accessed: (insert date).**

---



**Nemours National Office of Policy & Prevention**

1201 15th Street NW, Ste. 520, Washington, DC 20005 | 202.457.1440 | 202.649.4418 | [www.nemours.org](http://www.nemours.org)

©2020. The Nemours Foundation. Nemours is a registered trademark of the Nemours Foundation.

---

For more information, questions or comments please contact us at [mhcu@nemours.org](mailto:mhcu@nemours.org)