

How to **Engage**, **Empower**, and **Partner** with **DIVERSE** Communities for Policy Change

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BEYOND the Diagnosis

Why Families of Color *May Not See Themselves* in Your Organization—and How to Build Trust for Meaningful Policy Change

We all have
children with the
same diagnosis.

Isn't that
enough to bring
us together?



Yet many organizations find:

- Families of color **attend less frequently**
- **Leadership teams** lack representation
- Advocacy **participation is uneven**
- Policy conversations attract **the same voices repeatedly**

You may have even thought... well they must not care enough or as much as I do.

The **BETTER** question is:

"Why might they **NOT** see themselves here?"

~~"Why aren't they showing up?"~~

Shared Diagnosis $\neq$ Shared Experience

While families may share a diagnosis, they do not share:

- Educational experiences
- Healthcare experiences
- Economic realities
- Language access
- Cultural expectations
- **Experiences with systems and institutions**

Diagnosis is shared. **The experience is not.**

A Black mother, Latino father, immigrant family, and white suburban family may all love and advocate fiercely for their child.

But they often navigate entirely *different realities*.

BEFORE They Ever Walk Through Your Door

Many families of color have **already experienced:**

- Being ignored by schools
- Having concerns dismissed
- Steep communication barriers
- Healthcare bias/care being dismissed
- Under-identification or delayed diagnosis
- Over-surveillance and policing by systems
- Lack of representation/protection



By the time they find
your organization:

They are not entering
as blank slates.

They are arriving
with *experiences that
shape trust.*

Consider This

If your organization disappeared tomorrow:

- *Would families of color **notice**?*
- *Would they **feel a loss**?*
- *Would they believe their voice **mattered** there?*
- *Or would they feel like **guests** in someone else's community?*

Why or why not? How do you know? Pause for reflection.



What Inclusion Often Looks Like

Organizations frequently focus on:

- Diverse website photos
- Heritage month recognition
- Translation of materials

THESE DO MATTER!



But families are asking **deeper questions:**

- Who makes **decisions**?
- Who shapes policy **priorities**?
- Who is invited to **speak**?
- Whose **stories** are highlighted?
- Who has **influence**?

People can tell the difference between being represented and being included in change.

Trust is Built through **POWER**.

Families Trust Organizations That Share Power

Trust grows when families are:

- Asked for input early
- Included before decisions are made
- Invited to co-design solutions
- Compensated for expertise
- Seen as partners rather than recipients



Trust is built through **POWER**

Many organizations (*unintentionally*) ask families to participate **only after decisions are already made.**

It's disingenuous and families notice.

Why Policy Conversations **Often Miss** Families of Color

What are the
common barriers?



Common **BARRIERS**

Policy engagement often assumes families have:

- Time
- Transportation
- Childcare
- Knowledge of advocacy systems
- Comfort speaking publicly
- Fears of their lived experiences being exploited
- Prior relationships with leadership

The issue is often **NOT** motivation. The issue is **ACCESS**.

Ask a **DIFFERENT** question.

Stop Asking:

"How do we get families involved?"

Start Asking:

*"What would **need to be true** for families to believe this space was built with them in mind?"*

That shift changes everything.

Five Trust-Building Practices

- 1. Listen Before Leading-** *Conduct listening sessions before proposing solutions.*
- 2. Pay Families for Their Expertise-** *Treat lived experience as expertise.*
- 3. Diversify Leadership Pipelines-** *Not just volunteers—decision makers.*
- 4. Build Relationships Year-Round-** *Not only when you need feedback.*
- 5. Close the Loop-** *Show families how their feedback changed decisions.*

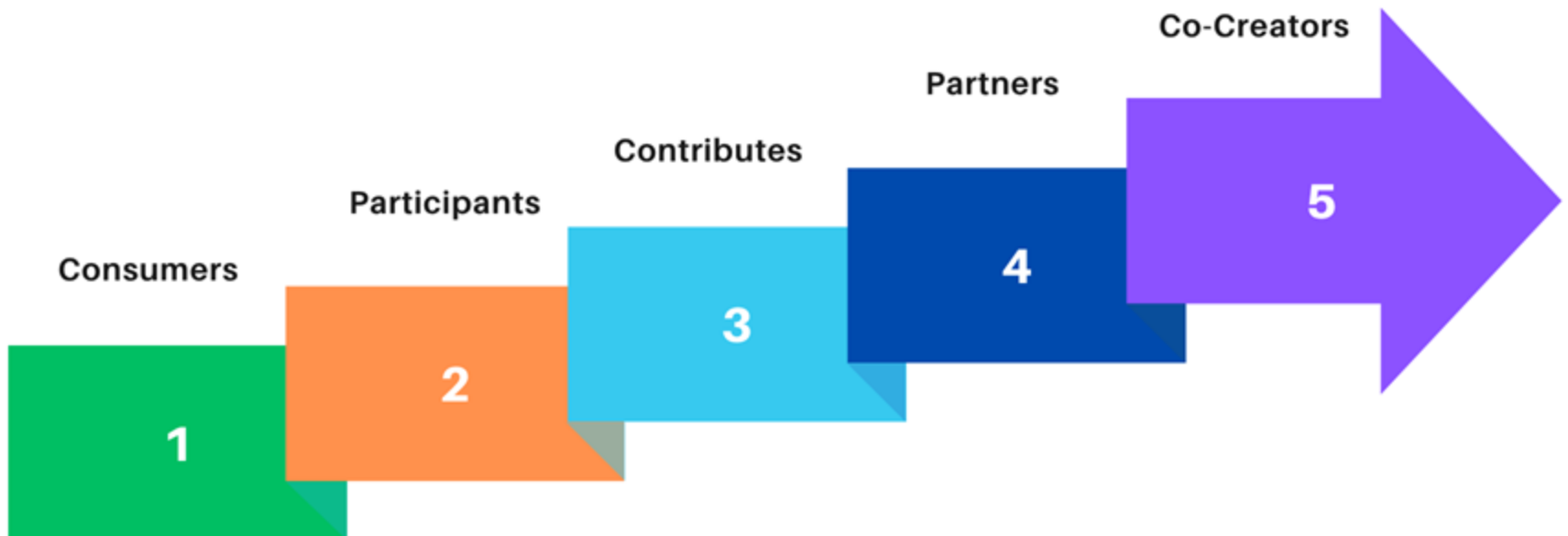
Trust grows when
people **see evidence**
that their voices **MATTER.**

The five trust building practices are practical and doable actions that any organization can take to feasibly create change.

Engagement *EVOLVES* as **YOU** do.

WHAT MEANINGFUL ENGAGEMENT LOOKS LIKE

Families move from:



Reflection Question

In your organization, are families of color primarily:

- Attendees?
- Volunteers?
- Advisors?
- Board members?
- Policy influencers?

What would it take to move one step higher?

The cost of **NOT** addressing this

When Families Don't See Themselves

Organizations lose:

- Valuable perspectives
- Better policy solutions
- Community credibility
- Future leaders
- Stronger advocacy efforts

The work becomes less effective for everyone.

The Opportunity

IMAGINE IF...

Every family believed:

- *"My voice matters here."*
- *"Someone understands my experience."*
- *"I can influence change."*
- *"This organization is for families like mine."*

That is where meaningful policy change begins. ***Not with policy. With trust.***



Closing Challenge

One Question to Take Back—

When families of color enter our organization:

Do they feel welcomed?

Or

Do they feel represented, valued, and powerful?

Those are not the same thing.

Families support what they help **CREATE.**

Trust is not built through outreach.

Trust is built through relationship, representation,
and **SHARED POWER.**

