

Re-Envisioning DIS/ABLED FUTURES

DISABILITY-LED PERSPECTIVES ON LONG-TERM SERVICES AND SUPPORTS



“We need a way forward that’s less costly
to our humanity and to taxpayers’ wallets.”

– David James Savarese, Founder & Facilitator
The Lives-in-Progress Collective @ The Alliance

THE FUTURE OF SELF-DIRECTION MUST BE DISABILITY-LED

Institutionalizing disabled people wastes resources while compromising our health and limiting our personal freedom. Self-direction is the only viable pathway within Home and Community-Based Services (HCBS), which provides Medicaid-funded, person-centered care to disabled people, **enabling us to live in our own homes and supporting our autonomy and dignity.**

WHY IT MATTERS: HOME-BASED CARE BUILDS BETTER LIVES & SAVES MONEY



**3X
LESS COSTLY**

Average annual Medicaid
long-term services and
supports spending per
person:

**HOME-BASED CARE
(HCBS)
\$17,298**

**INSTITUTIONAL CARE
\$54,462**



**23–30%
LOWER COSTS**

National evaluations found
Medicaid costs were
**23–30% lower after
transition into
home-based settings.**



**90%+
PREFER
HOME-BASED**

More than 90% of people
with disabilities want
to live in their
homes—not in
institutions.

POLICY RECOMMENDATIONS: THE FUTURE OF SELF-DIRECTION MUST BE DISABILITY-LED



1. EXPAND SELF-DIRECTION

Expand truly participant-
directed self-direction
models with more
flexibility, autonomy,
and control.



2. DISABILITY-LED GOVERNANCE

Ensure a disabled
majority in governance
and oversight of
self-direction policy
development,
implementation, and
evaluation.



3. REDUCE BARRIERS

Reduce unnecessary
bureaucratic barriers
and move resources
directly to
individuals and
administrative layers.



4. ESTABLISH CROSS- DISABILITY-LED ORGANIZATIONS

Establish cross-disability-
led organizations, such
as LIPC, as partners in
self-direction policy
and systems design.



5. CENTER EQUITY & INCLUSION

Ensure leadership and
participation from
historically marginalized
disability communities.



**SELF-DIRECTION IS NOT SIMPLY A SERVICE MODEL.
IT IS THE RIGHT TO DIRECT OUR OWN LIVES.**

NOTHING ABOUT US WITHOUT US

COLLECTIVELY LEADING THE WAY



WE DESIGN
OUR OWN LIVES

WHERE ARE WE?

In their Affordable Home Care Guarantee letter, Senators Sanders and Booker outline an important vision for expanding care. The comparison below highlights how the proposal could be strengthened through a disability-led lens.

THE CURRENT LETTER SAYS...

DISABILITY-LED POLICY MUST SAY...



WHO COMES FIRST?

Focus on American families—affordable, high-quality Home Care in the setting they choose, with good jobs for workers.

Start with the person receiving support. When disabled people and older adults have the resources, autonomy, and supports they need, families, caregivers, and workers benefit too.



ECONOMIC OPPORTUNITY?

Raise financial limits for families.

Raise income and asset limits so disabled people can work, save, build wealth, and pursue their goals without losing essential supports.



COMMUNITY & RELATIONSHIPS?

Build innovative volunteer models that mobilize community members to care for one another.

Invest in authentic, interdependent networks of support that strengthen community connections, peer mentorship, and self-determination.



SYSTEMS DESIGN?

Ensure Home Care is a dependable and integrated part of the Home Care system.

Ensure self-direction and community living are fully integrated into housing, employment, and support systems.



FINANCIAL SECURITY?

Guarantee middle-income families can access care without depleting their savings.

Replace poverty-based eligibility with flexible, person-centered supports that promote independence, opportunity, and economic security.



WHOSE FUTURE DO WE BUILD?

90% of people with disabilities prefer to live in their own homes. As soon as we decide 10% want nursing homes, we condone segregation.

More than 90% of disabled people want to live in their homes and communities. Public policy should make home-based living the expectation, not institutionalization the alternative.



OUR PRIMARY ASKS

- 1 Promote the policy changes outlined in this brief.
- 2 Educate your Senator and colleagues about the importance of self-direction, home-based living, and disability leadership.
- 3 Apply a disability lens to the Home Care Guarantee and future LTSS policies.
- 4 Introduce us to Senate offices that have not yet engaged with disability-led advocates.



OUR SECONDARY ASK

Partner with the Lives-in-Progress Collective (LIPC) and other disability-led organizations to develop and implement the Home Care Guarantee.



At least 50% of members on implementation, advisory, oversight, and evaluation bodies should be people with disabilities with lived experience.

WHAT IS LTSS?

Long-Term Services and Supports (LTSS) are the services and supports people may need over time due to disability, chronic conditions, or aging. They help people live with dignity, choice, and control—in the place they call home.



CONNECT WITH US



DJ Savarese
djaavarese@gmail.com
Lives-in-Progress Collective (LIPC)
citizendirectedsupports.org



Monica Mesa-Alvarez, PhD
nmesa@natleadership.org
National Leadership Consortium on
Developmental Disabilities
natleadership.org

Let's build a future where
disabled people lead,
choose, and thrive.

