

Who Gets to Be in the Room: Access and Representation

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Access shapes voices

Representation is not just about expertise:

- Access to global spaces is shaped by systems, not only ideas
- Mobility, funding, and logistics decide who shows up
- When travel becomes a test of privilege, voices disappear quietly



The blind spot: Young adults

Great at starting lives, weaker at supporting them

- CI care focuses (rightly) on childhood
- Teenagers and young adults become socially and professionally invisible
- Missing voices lead to systems that don't fit real adult lives



The hidden challenge: Funding

Lifelong care cannot be funded like a one-time event

- CI care is lifelong: upgrades, maintenance, continuity
- Young adults fall into the gap between pediatric and adult systems
- When costs become personal, inequality becomes predictable



What actually changes systems

Presence + funding + policy language

- Representation needs intentional funding
- Lived experience is not a pity story - it's a design brief
- Continuity of care is an education, employment, public health, and economic issue



Take-home

Voices don't disappear because
they don't exist.

They disappear because access is
uneven - and uneven systems
can be redesigned.

