Earning, Measuring, and Growing Trust

A research view on DDS's role in building trust with California's developmental disability community

A research brief from the Self-Determination Tech Alliance (SDTA), a self-advocate– and family-facing nonprofit. · June 2026 Short on purpose; the research is in the footnotes.

Why this exists

Most "trust" conversations end up as a complaint list. This one doesn't.

SDTA is a small organization that shows up to support self-advocates and families. We pulled together what the research says about trust — **how a public agency earns it, measures it honestly, and strengthens it over time** — and what it means for DDS's role in serving this community. It's offered in a collaborative spirit: DDS owns the decisions; this is the research, and where we think it points.

It's a short, plain-language read, written for busy people. Read the bold lines and you have it in two minutes; the footnotes are there if you want to go deeper.

One honest caveat: we read this research through a **lived-experience, advocacy lens** — what it means for the self-advocates and families navigating the system. The formal studies come from many fields (government, health care, social care, the courts), and on any single point the academic mileage varies — we've flagged the real debates in the footnotes. We're after what's *useful and true enough to act on*, not a literature review.

This isn't a report card. As the brief shows, DDS already does a good deal of what the research points to — so the aim is to show *why* those things matter, and the next step worth taking.

The one big idea

> **Trust is not the same as being liked. Trust is a bet.**

When a family trusts your agency, they are making a bet. They are saying: *"I will rely on you, even though I can't control what you do."* [1]

That is why trust feels risky to families — and why it is so valuable when you earn it.

A satisfaction score asks, *"Did you like that?"* Trust asks, *"Will you rely on us again next time it matters?"*

Those are different questions. An agency can score "okay" on satisfaction and still have families who do not trust it.

Where to start: one easy win, one high-impact move

Two moves the research points to most clearly — here in brief; **the evidence for each is in the sections that follow.**

The easy win — a family-impact self-check. Before the next directive goes out, run it through a one-page, five-question check from the family's point of view. No new staff, no new system — it just makes the family's seat a required stop before publication, and it's the single most do-able move here. *(It's the research below on fair process — how a decision is made — applied to directives.)*

The high-impact move — responsiveness, in two parts. Families' top barrier is *slow or no response* [2] [3] — the **number-one barrier** they named in a community survey this spring (SDTA, 2026). Two changes go straight at it:

a. Establish a response expectation — a real human response from the Regional Center. [4] When a Regional Center can't resolve a request right away, the family is told *when* they'll hear back. No one is left in silence. The near-term ask is small: **accept the standard** now, and build it into the statewide system's measures once **LOIS** — the new statewide case-management system replacing the Regional

Centers' legacy systems — is in place. Until then it can be tracked from the family's side — through community surveys and navigation tools, **published on a regular, public cadence** so it can't quietly drift, and so it isn't graded by the centers on their own homework. And to be clear, this is a standard the **whole system commits to together — DDS and the centers alike** — not a yardstick aimed at the Regional Centers. No one expects it met overnight; families already know that. What changes is that *answering* becomes the standard, not the exception.

b. Move easy decisions closer to families. Let service coordinators directly approve the low-risk, in-policy calls — for example, **adding a service that's within purchase-of-service guidelines**, or a **routine, in-policy Spending Plan adjustment that stays within a person's existing IPP goals.** This is also the most realistic way to deliver (a): every routine request a coordinator can settle without a chain of internal approvals and status-chasing is a faster answer for the family — and overhead saved per request. [5]

What the research says builds trust

Across 22 countries and more than 50,000 people, the OECD found that trust in a public institution rests on **five things**, in two groups: [2]

Can we count on you? (competence)

- **Responsiveness** — you answer, and you answer in time.
- **Reliability** — you do what you said you would do.

Are you on our side? (values)

- **Openness** — people can see how decisions are made.
- **Integrity** — you act on principle, not on who has the most pull.
- **Fairness** — people are treated equally, and the rules apply the same to everyone.

Takeaway for an agency: trust is not a mood. It is built from five things you can actually work on.

The often-missed finding: *how* you decide shapes trust, not just *what* you decide

Researcher Tom Tyler studied this for decades. He found that people judge an authority as fair — and decide whether to trust it — based heavily on **how they were treated**, not only on whether they got the answer they wanted. [6] Strikingly, even many people who *don't* get the help they ask for still see an authority as fair and legitimate **when the process was fair.**

Fair process has four parts: - **Voice** — people get to be heard *before* a decision. - **Neutrality** — decisions are made on facts and consistent rules, not bias. - **Respect** — people are treated with dignity. - **Honest motives** — people believe you are trying to do right by them.

Takeaway for an agency: a "no" delivered with voice, a clear reason, and respect can *keep* trust. A "yes" delivered coldly — or a decision made with no explanation — can lose it.

→ The easy win we opened with — the family-impact self-check — is exactly this: fair process, applied before a directive ships.

The thing that quietly destroys trust: silence

When a family asks for something and hears **nothing back**, that is not neutral. It is corrosive.

The research on "administrative burden" shows that the hardest costs families carry are often invisible: the time spent searching for answers, the stress, and the sense of being powerless in the process. [7]

There is even a legal echo of this idea. In federal rule-making, agencies have a **duty to consider and respond** to significant public input — and courts have said a key reason is that a reasoned response **builds public trust** and treats people as

owed an explanation. The principle travels well beyond rule-making: people deserve an answer, not silence. [3]

Takeaway for an agency: an unanswered request is not a small service gap. It is a trust event. *"We don't know yet, here's who's looking into it, here's when you'll hear back"* protects trust. Silence spends it.

→ This is the evidence behind move (a) we opened with — a response expectation that someone answers, and says when.

Why trust is fragile for *these* families in particular

Families of people with intellectual and developmental disabilities are not starting from zero. For many, they are starting from **below** zero — and for good reasons.

- In the disability world, protections have rarely been *handed* to families — nearly every right was **won through hard-fought advocacy**: rallies, protests, lawsuits, and families who refused to be ignored. Families know the gains came from pushing. That history is part of the relationship, whether a system names it or not.
- In healthcare, mistrust among marginalized groups is **real, measurable, and linked to people avoiding care.** [18] The same pattern is visible in our own system: in DDS's data, the share of eligible people receiving **no** purchase-of-service funds ranges from about **9.7% to 25.9% across Regional Centers** — a sign that, for many families, the door isn't yet fully open. [19]
- And here is the key research finding: mistrust is driven less by knowing about a famous historical wrong, and **more by ongoing, present-day experience** — being treated unequally *now.* [20]

Takeaway for an agency: you don't earn trust by saying "that was the past." You earn it by making the *present* experience fair — especially for the families who have the least reason to expect it.

The disparity families feel — and what DDS is already doing about it

In California, families don't have to read a study to feel this. They live it.

Here's something most public systems never do: **DDS measures its own equity gaps and publishes them.** Every year, under state law (W&I Code §4519.5), DDS and Regional Centers compile purchase-of-service spending data broken down by race, ethnicity, and primary language, post it publicly, and hold community meetings about it. [8] Shining a light on your own performance — *including where it falls short* — is exactly the **openness and integrity** the research puts at the heart of trust. [2]

And the data are honest. An analysis of DDS's published numbers found one Regional Center authorizing about **$30,920 in services per white consumer and $14,423 per Latinx consumer** — and statewide, DDS's data show Hispanic and Black Californians receiving lower average purchase-of-service funding than white consumers. [9]

And DDS isn't only *watching* that gap — it's **funding work to close it**, through Service Access & Equity grants that have put **millions of dollars since 2016** into reaching underserved families. [10]

This is not framed here as anyone's bad intent. It is a **system-design gap** — one DDS already measures *and* is investing to close.

Takeaway: the data, the mandate, and the community meetings already exist. Closing the gap is *hard* — it has stayed stubborn in places despite a decade of real investment, and no one should pretend a single move fixes it. But trust doesn't only track the dollars: families' sense that the system is **fair and responsive** can move *now*, even while the harder spending gap is still being worked — and that responsiveness is the lever this brief is really about.

How trust grows: build the arc

Trust is rarely won with one big gesture. It grows as an **arc** — a series of small, visible, kept promises that add up. The research points to three moves that bend the arc upward, and every one of them can start today.

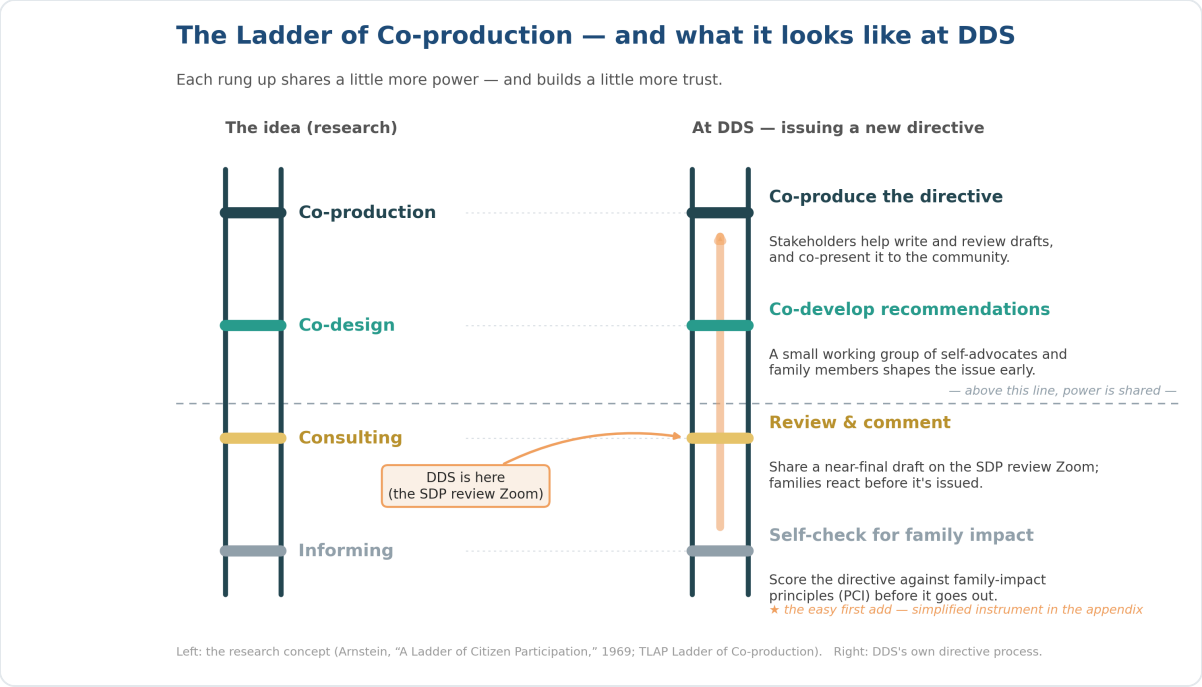
1. Actions, not just words. Studies on building back trust are blunt: an apology or a promise, by itself, rarely moves the needle. What moves it is a **voluntary, substantive action** — something you did *not* have to do, that shows real intent. [11]

2. Match the response to the moment. - When something went wrong because of a **mistake** (a competence gap), an honest acknowledgment and a visible fix work well. - When families feel a decision wasn't **on the level** (an integrity question), words alone can backfire — only changed behavior, repeated and visible, rebuilds confidence. [12]

3. Share the power, don't just gather opinions. The strongest trust-builder of all is letting the people you serve **help shape the decisions — *before* they are made.** This is where most systems fall short: in the OECD's survey, only about **3 in 10 people felt they had any real say** in what their government decided, and only about a third believed their input would actually be used. [13]

Back in 1969, Sherry Arnstein drew a "ladder" of participation: at the bottom, informing and consulting people; at the top, genuinely sharing power. Her warning — *participation without real power is "an empty ritual."* [14] The disability and social-care field built on this with the **Ladder of Co-production**: the goal isn't to *consult* families, it's to work with them **as equals** in designing and running services. [15] (Done well, it has to be *resourced* and reach *beyond the usual few* — especially the families with the least time to show up — or it slides back into the "empty ritual" Arnstein warned about.)

Here's the research concept side by side with what each rung looks like in DDS's own work — issuing a new directive:



DDS is already at **Review & comment** — sharing a near-final directive on the community Zoom, real consultation that most agencies never reach. From here the arc extends two ways: the **easy foundational add** beneath it — a quick **self-check of every directive against family-impact principles** before it goes out — and the rungs above it: a small **working group** of self-advocates and family members that helps shape the issue *before* drafting, then **co-producing** the directive with families who help write, review, and co-present it. None of it requires new money or new structures; it moves the same conversation earlier and wider. Each rung shares a little more power — and, the research says, builds a little more trust.

This is the same truth the disability rights movement put into five words a generation ago:

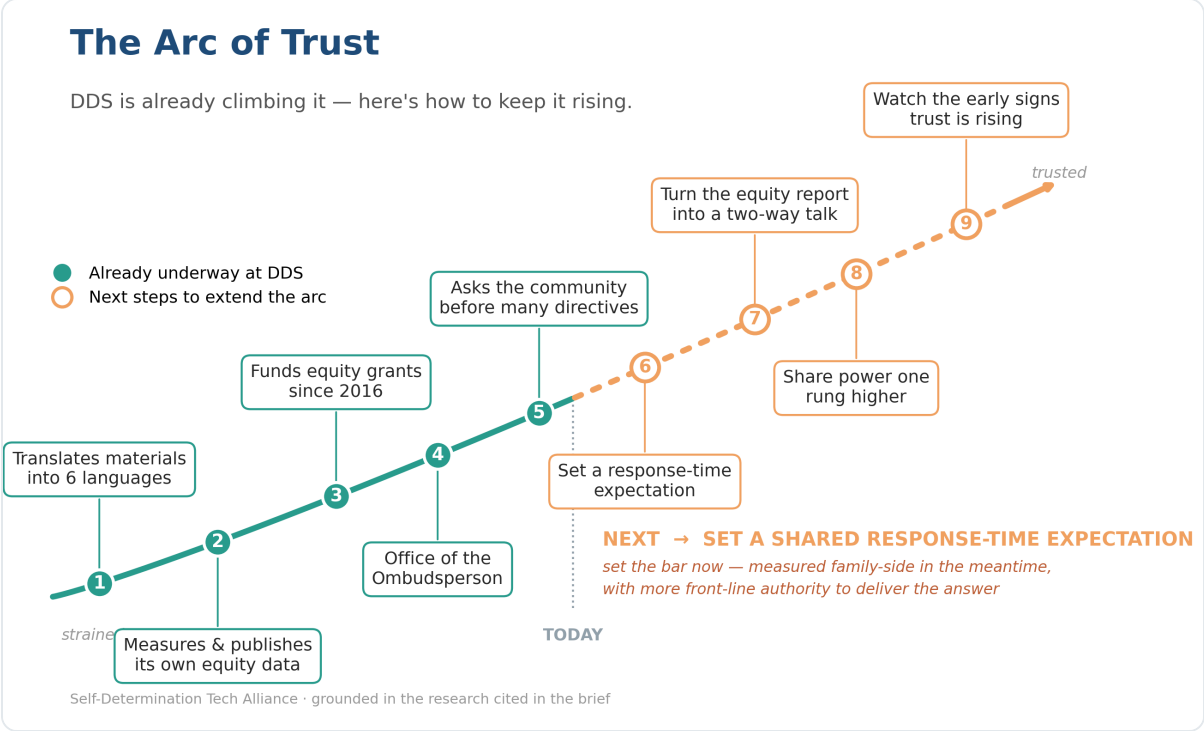
> **"Nothing About Us Without Us."** [21]

It's not a slogan. It's a design principle — and a trust strategy. People trust what they helped build. And research on self-determination supports it: more self-determination is linked to better employment and independent-living outcomes, and trials show it can be taught. [16]

And the best part: every step is visible. You don't have to wait for trust to "arrive" — the early signs show up in how families act long before any survey catches up.

DDS is already on the arc

DDS isn't starting from zero. Much of what the research points to is **already underway** — and still being built on:



- **DDS meets families in their language.** Its Language Access Plan publishes vital documents in six threshold languages and offers free interpretation on request. [22] That is DDS recognizing what the research warns about: an English-only system screens out the families who need help most.
- **DDS measures its own equity — and publishes it.** Every year, DDS posts purchase-of-service data by race, ethnicity, and language, and holds community meetings on it. [8] Measuring your own gaps *in public* is the **openness and integrity** the research puts at the center of trust. [2]

- **DDS acts on what it finds.** It backs the equity data with real funding, not just reports. [10] That is **reliability and follow-through**.
- **DDS built a place to be heard.** The **Office of the Ombudsperson** (established 2022) gives families a neutral place to raise concerns, get information, and have their complaints fed back to decision-makers. [23] That is **procedural justice — voice and recourse — built into the org chart.**
- **The SDP team asks before it acts.** The Self-Determination Program team's practice of holding a community feedback session before issuing many directives is, in research terms, **voice before a decision** — Tyler's single most important element of fair process. [6]

The takeaway: these are not starting points — they're a foundation most public systems never build. The arc now bends toward one move families would feel first: **establishing a response-time expectation the system works toward** (with the front-line authority that frees the time to meet it) — then the dashed steps above: turning the equity report into a two-way conversation, sharing power one rung higher, and watching the early signs that trust is rising.

The short version

The research doesn't ask DDS to become something new — only to **answer in time, decide fairly, measure honestly, share power, and keep its word**, where families can see it. Five lines to remember:

1. **Trust is a bet families make on you — not a satisfaction score.** [1]
2. **How you treat people shapes trust as much as whether they get a yes.** [6]
3. **Silence is a trust event — start by setting a response expectation (a human reply, and *when*).** [3]
4. **Measure the gap between groups, in every language — not just the average.** [24]
5. **Share power and act on what you hear — trust grows as an arc of kept promises, and DDS is already building it.** [14] [10]

The opportunity is simply to **keep extending the arc DDS is already on** — each kept promise, made visible, is the next step.

We put this together in support of the families and self-advocates we all serve. If any of it helps DDS, even a little, it was worth it.

About SDTA

The Self-Determination Tech Alliance is a small, **self-advocate– and family-facing nonprofit**. We'll keep looking for practical, collaborative ways to support California's developmental disability community — and to work alongside the people and agencies who serve it. This research is offered in that spirit.

Acknowledgements

This work stands on the shoulders of the people who fought — and still fight — for the right of people with disabilities to be heard. We're grateful to the many hard-working people inside the system — at **DDS**, the **Regional Centers**, and the **State Council on Developmental Disabilities (SCDD)** — who show up for families every day; and to the advocates who have carried this cause for decades, including **Disability Voices United**, **Disability Rights California**, and the **Integrated Community Collaborative (ICC)**. These recommendations are made in recognition of the efforts of everyone above — families, advocates, and the people inside the system. SDTA's aim is to **amplify and corroborate** that work, not to claim credit for it.

Appendix A — The family-impact self-check (a simplified PCI)

A one-page check DDS can run on any new directive *before* it goes out — answered from the family's point of view. (Simplified from the longer version SDTA shared earlier.) Mark each 🟢 / 🟡 / 🔴 and add one line on what to fix.

#	Ask, from the family's seat	🟢 / 🟡 / 🔴
1	**Easier or harder?** Does this make the path easier — or add steps, forms, or waiting?	
2	**Could it cost someone a service?** Could it narrow, delay, or condition a service a person already relies on?	
3	**Will people get it — in time, in their language?** Will affected families learn about it, understand it, and be able to act, in their language, before it takes effect?	
4	**Does it widen or narrow the gap?** Will it help close the equity gaps DDS already measures — or quietly widen them?	
5	**A way to push back, and a name attached?** If it goes wrong for a family, is there a clear way to appeal — and a named person responsible for answering?	

How to read it: any 🔴 is a stop-and-fix before release; several 🟡 means look again; all 🟢 is the goal, not a finish line. *One honest note: sometimes the family's-eye answer is hard because a statute or court order ties DDS's hands. Name that plainly — and still fix the parts DDS controls.*

Appendix B — One caution from the research: transparency alone isn't enough

Publishing data and adding oversight do **not** automatically build trust — and can even lower it. Philosopher Onora O'Neill found that piling on disclosures, forms, and accountability checks can signal a "culture of suspicion" rather than earn confidence. [17] The lesson isn't *less* openness — it's that transparency builds trust only when it **leads to visible action and kept promises**, not box-checking. (It's exactly why DDS publishing its equity data *and then acting on it* is the trust-building kind.)

Sources & footnotes

All sources below were independently verified. Findings from single studies are described as "linked to" or "associated with," not as proven cause. Statistics are quoted with their original scope.

Notes on use: This brief is written to be read in minutes and trusted on the details. It pairs general research with California-specific facts, and it deliberately credits the trust-building work DDS already has underway — the equity measurement, the Service Access & Equity grants, the Office of the Ombudsperson, and the SDP team's community feedback sessions. It is bilingual-ready — a Spanish version can follow. Tone is intentionally collaborative: disparities are framed as system-design gaps to close together, never as anyone's bad intent. — SDTA, June 2026

---

1. **What trust is.** The OECD defines trust as "a person's belief that another person or institution will act consistently with their expectation of positive behaviour." The classic scholarly definition is "a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behavior of another" — requiring both *risk* and *interdependence* (you cannot get what you need without relying on the other party). Rousseau, Sitkin, Burt & Camerer (1998), "Not So Different After All: A Cross-Discipline View of Trust," *Academy of Management Review* 23(3):393–404. See also OECD, *Guidelines on Measuring Trust* (2017). The research treats trust as **distinct from satisfaction**. ↩↩

2. **The five drivers of trust.** OECD identifies five drivers in two clusters — *competence* (responsiveness, reliability) and *values* (openness, integrity, fairness). OECD, *Building Trust to Reinforce Democracy* (2022), drawing on the OECD Survey on Drivers of Trust in Public Institutions; and *An Updated OECD Framework on Drivers of Trust in Public Institutions* (2024). ↩↩↩↩

3. **The duty to respond — why silence erodes trust.** Legal scholars argue that requiring agencies to give a reasoned response to those affected "promotes public trust in the outcomes of the administrative process" and serves a dignitary function — treating people disadvantaged by a decision as "entitled to an explanation" (Levin, 2024, "The Duty to Respond to Rulemaking Comments," *Yale Law Journal Forum*, drawing on Mashaw's dignitary theory of due process). The narrower legal hook: in federal rule-making an agency "must consider and respond to significant comments" (*Perez v. Mortgage Bankers Ass'n*, 575 U.S. 92 (2015); failure-to-respond doctrine reaffirmed in *Ohio v. EPA*, 2024). We cite this as the *principle* that people are owed an answer, not as a rule that governs individual Regional-Center decisions. *Also relevant:* providing information measurably helps — IRS reminders about the Earned Income Tax Credit produced a 41% jump in take-up among initial non-claimants (Bhargava & Manoli, summarized in Moynihan, Herd & Harvey 2015). ↩↩↩

4. **Why the standard must mean a *real* response.** Crude public-sector timeliness targets are well known to invite "gaming" — hitting the metric while missing the point (e.g., appointment-booking practices that technically met England's health-access targets without improving care). Bevan & Hood (2006), "What's Measured Is What Matters: Targets and Gaming in the English Public Health Care System," *Public Administration* 84(3):517–538. The lesson: measure a genuine human response, paired with the front-line capacity to give one — never an auto-acknowledgment. ↩

5. **Empower the front line.** Frontline public workers — social workers, service coordinators — exercise broad discretion and effectively shape policy at the point of delivery; in Michael Lipsky's classic formulation, the real policy is less what is written than what is implemented, and these workers' caseloads and working conditions determine the quality of service families actually receive. Michael Lipsky, *Street-Level Bureaucracy: Dilemmas of the Individual in Public Services* (Russell Sage Foundation, 1980; 30th-anniversary expanded edition, 2010). ↩

6. **Procedural justice — how you decide shapes trust independently of the outcome.** Tom R. Tyler's body of work establishes the "fair process effect": people judge authorities as legitimate based on the fairness of the *process* (voice, neutrality, respect, trustworthy motives), not only on whether the outcome favored them. In Tyler & Huo's research, ~30% of people who called police reported the problem was not solved, yet inability to help "was not a central concern; rather, people evaluated the police by the justice of their procedures." Tyler & Mentovich (2023), "Mechanisms of Legal Effect: Procedural Justice Theory," Center for Public Health Law Research, Temple University (summarizing Tyler & Huo, *Trust in the Law*, Russell Sage, 2002; and Tyler, *Why People Obey the Law*, 1990/2006); the four-element framing is also the basis of the U.S. National Initiative for Building Community Trust and Justice. *Caveat:* the causal direction is debated — legitimacy beliefs may shape fairness perceptions as much as the reverse, and several procedural-justice field experiments have not replicated (Nagin & Telep, 2017, *Annual Review of Law and Social Science* 13:5–28). We treat fair process as shaping trust *alongside* outcomes, not as a proven lever that outweighs them. ↩↩↩

7. **Administrative burden — the invisible costs families carry.** Burdens come in three forms: *learning costs* (finding out what exists and whether you qualify), *psychological costs* (stigma, loss of autonomy, stress), and *compliance costs* (forms, documentation, rules). These burdens "diminish the effectiveness of public programs" and shape "people's perceptions of government." Moynihan, Herd & Harvey (2015), "Administrative Burden," *Journal of Public Administration Research and Theory* 25(1):43–69; Herd & Moynihan (2018), *Administrative Burden: Policymaking by Other Means*, Russell Sage Foundation. This literature is explicitly grounded in procedural justice (Lind & Tyler 1988), and cross-national research finds "fair and equitable processes matter more than assessments of government performance" for citizen trust (Van Ryzin 2011). ↩

8. **The existing legal mandate (the good news).** California Welfare & Institutions Code **§4519.5** requires DDS and Regional Centers to annually compile purchase-of-service data **disaggregated by the consumer's race or ethnicity and primary language** (and by age, disability, residence type, and the number eligible but receiving no POS funds); to **post the data publicly** by year's end; for each Regional Center to **meet with stakeholders in a public meeting** within three months, conducted in a "culturally and linguistically appropriate" manner; and to determine whether disparities exist and, if so, provide "recommendations and a plan to promote equity, and reduce disparities." Cal. Welf. & Inst. Code §4519.5; see DDS Purchase of Service Data page (dds.ca.gov). ↩↩

9. **The California purchase-of-service disparity — DDS's own data.** Under §4519.5, DDS compiles and publishes purchase-of-service expenditure data by race/ethnicity and primary language. Analyzing *that DDS data*, Disability Rights California (*Differences in Regional Center Spending*, March 2023) highlighted one (anonymized) Regional Center authorizing, in 2021–22, about **$30,920 per white consumer vs. $14,423 per Latinx consumer** (and $14,919 per Asian consumer) — "more than double" — and the same DDS data show the statewide pattern: Hispanic and Black consumers receiving lower average purchase-of-service funding than white consumers. (DRC is quoting DDS's published figures, not a separate study.) Framed here as a **system-design gap to close**, not an indictment. California Department of Developmental Services, Purchase of Service / disparities data (dds.ca.gov/rc/disparities/data/). ↩

10. **DDS already acts on the data — the Service Access & Equity grants.** Since 2016, DDS's Service Access & Equity (SAE) grant program — also called the Disparity Funds Program — has put **millions of dollars** toward helping people with intellectual and developmental disabilities from diverse backgrounds gain equal access to services, awarding **more than 500 grants** to community-based organizations and Regional Centers (for example, $22 million to 75 organizations in the 2022–23 cycle). Funding has varied year to year. California Department of Developmental Services, "Service Access & Equity / Disparity Funds Program" (dds.ca.gov/rc/disparities/disparity-funds-program/). ↩↩↩

11. **Building trust back — words aren't enough.** Repairing trust requires *voluntary, substantive* action, not just apology: studies find that voluntarily adopting monitoring/sanctions restores trust, while the same measures *imposed* from outside do not — because only voluntary acts signal genuine intent. Kim, Dirks & Cooper, "The Repair of Trust" (*Academy of Management Review*); Nakayachi & Watabe (2005), *Organizational Behavior and Human Decision Processes* 97(1):1–17. ↩

12. **Match the repair to the type of break.** Kim, Ferrin, Cooper & Dirks (2004) found trust was repaired more successfully when wrongdoers **apologized for competence-based violations but denied culpability for integrity-based violations** — for integrity violations, an apology can backfire. The mechanism is asymmetric weighting: people weight positive information about competence more heavily, but negative information about integrity more heavily. Kim, Ferrin, Cooper & Dirks (2004), "Removing the Shadow of Suspicion," *Journal of Applied Psychology* 89(1):104–118. ↩

13. **The voice / responsiveness gap.** OECD's 2021 Survey on Drivers of Trust in Public Institutions (22 countries, 50,000+ respondents) found only ~30.2% of people felt the political system let them have a say in what the government does, and only ~32.9% thought their government would adopt opinions expressed in a public consultation. OECD, *Building Trust to Reinforce Democracy* (2022). ↩

14. **The ladder of participation.** Sherry Arnstein, "A Ladder of Citizen Participation," *Journal of the American Institute of Planners* 35(4):216–224 (1969). Eight rungs grouped into nonparticipation, tokenism, and citizen power; the core argument that "participation without redistribution of power is an empty and frustrating process for the powerless." ↩↩

15. **Co-production — service users as equal partners.** The UK Think Local Act Personal (TLAP) "Ladder of Co-production," developed by its National Co-production Advisory Group (explicitly drawing on Arnstein 1969), defines co-production as "when people come together as equals to make decisions or create services that work for them all," with service users and carers "valued by organisations as equal partners" who "share power and have influence over decisions." Consultation ranks as a *lower* rung than co-production. Think Local Act Personal, "Ladder of Co-production." ↩

16. **Self-determination improves outcomes.** Research links higher self-determination among people with intellectual and developmental disabilities to better post-school employment and independent-living outcomes, and randomized trials show interventions can causally raise self-determination and goal attainment. Wehmeyer & Schwartz (1997), "Self-Determination and Positive Adult Outcomes," *Exceptional Children* 63(2):245–255; Shogren, Wehmeyer et al. (2018, 2019), studies of the Self-Determined Learning Model of Instruction. ↩

17. **The transparency paradox.** Onora O'Neill argues the real problem is often a "culture of suspicion" rather than a true "crisis of trust," and that expanding accountability and disclosure mechanisms intended to restore trust can paradoxically erode it; she advocates "intelligent accountability." O'Neill (2002), *A Question of Trust: The BBC Reith Lectures 2002*, Cambridge University Press. ↩

18. **Mistrust is real and linked to disengagement.** Among urban Black men, those without a recent physician visit had significantly higher medical-mistrust scores (2.73 vs. 2.36); mistrust correlated negatively with perceived access to care and positively with avoidance of care. (Cross-sectional data — associations, not proven cause.) Shelton, Winkel, Davis et al. (2010), *Journal of General Internal Medicine* 25:549–555. ↩

19. **Eligible, but receiving no services.** Under W&I §4519.5, DDS reports the number and share of people found eligible for Regional Center services who receive *no* purchase-of-service funds in a year. That share varies widely by Regional Center — in **FY 2024–25**, from roughly **9.7% to 25.9%**. Source: DDS FY 2024–25 Annual Purchase of Service reports (per W&I §4519.5); compiled by SDTA, April 2026. ↩

20. **History matters — but present-day experience matters more.** Brandon, Isaac & LaVeist (2005) found that *knowledge of* the Tuskegee Study did not by itself predict trust in medical care, and attributed racial differences in mistrust to broader historical and personal experience rather than awareness of a single event. (A stronger-design study, Alsan & Wanamaker (2018), *Quarterly Journal of Economics*, found the 1972 *disclosure* of Tuskegee did correlate with increased mistrust and worse health among older Black men.) The practical takeaway: ongoing lived experience and unequal treatment drive mistrust — historical harm still matters, but the present is where trust is won or lost. Brandon, Isaac & LaVeist (2005), "The Legacy of Tuskegee and Trust in Medical Care," *Journal of the National Medical Association* 97(7):951–956. ↩

21. **"Nothing About Us Without Us."** James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment*, University of California Press (1998). Charlton traces the phrase to disability-rights leaders in South Africa in 1993; the book frames it as a "political philosophy of self-determination," expressing the conviction that people with disabilities know what is best for them. The principle is foundational to the disability-rights movement and the UN Convention on the Rights of Persons with Disabilities. ↩

22. **DDS meets families in their language.** The DDS Language Access Plan ensures vital documents are available in the department's six threshold languages — Spanish, Vietnamese, Tagalog, Korean, Simplified Chinese, and Traditional Chinese — and DDS customers can request free verbal and sign-language interpretation and written translation in their own language. California Department of Developmental Services, "Language Resources" / Language Access Plan (dds.ca.gov/general/language/). ↩

23. **DDS built a neutral place to be heard — the Office of the Ombudsperson.** Funded through the 2022 Budget Act and operational December 1, 2022, the Office of the Ombudsperson assists individuals and families applying for or receiving Regional Center services under the Lanterman Act — providing information, facilitating resolution of disagreements and complaints, making recommendations to DDS and the Legislature, and compiling and reporting data. California Department of Developmental Services, "Office of the Ombudsperson" (dds.ca.gov/initiatives/office-of-the-ombudsperson/). ↩

24. **Why the average lies — and why English-only filters out the most affected.** Among Latino parents, the Group-Based Medical Mistrust Scale behaved differently by language (reliable in Spanish, α=0.76; weaker in English, α=0.61). Overall mistrust scores were nearly identical between English- and Spanish-speaking parents (27.48 vs. 28.74, *not* a significant difference) — yet item-level patterns diverged by language. Aggregate scores can therefore mask real cross-group differences. Martinez, Huh & Tsui (2022), "Validating the Group-Based Medical Mistrust Scale with English and Spanish Speaking Latino Parents," *Journal of the American Board of Family Medicine* 35(2):244. The implication: a single average — or an English-only instrument — hides the families most likely to be underserved. ↩