The 2am Problem:
Why the disability services system leaves most families on their own — and what we're doing about it

A position paper on DAN, the Disability Access Navigator — a navigation program built to level the playing field for families navigating California's developmental disability services system.

WHERE THIS STARTS
It's 2am. Your phone is the only help available.

You've just heard about something called Self-Determination and you want to understand it. Or you're sitting with a new diagnosis and trying to figure out where to even begin. Or you know you need something for your family member but you're not sure how to ask for it — or even who to ask. The office is closed. Your service coordinator doesn't answer after hours. You don't know where to find an advocate, or you're not sure you can afford one. And the system you're trying to understand was built by people who already understand it.

This is the moment DAN was built for.

I'm Beth Martinko, founder of Captain's View Advocacy and program architect of DAN. I've spent years sitting across from families in exactly this position — overwhelmed, underinformed, and alone in a system that should be — and wants to be — working for them. DAN is my attempt, with a growing team of advocates, technologists, and people with lived experience, to make sure no family has to navigate that alone. Not at 2am, and not ever.

THE ORIGIN STORY
My son Josh made it through. Most people don't.

My son Josh is a self-advocate. He entered California's Regional Center system through the traditional program — the path that most families take. The services there weren't the right fit for him. But five years ago, after learning about the Self-Determination Program, Josh transitioned. And he started thriving.

Self-Determination — known as SDP — gives Regional Center clients a real budget based on their goals and the right to direct their own services. It's one of the most powerful options available to people in California's developmental disability system. There is no special eligibility barrier to enter it. Any Regional Center client can apply.

> *'Josh made it because I knew how to navigate the system. I knew what questions to ask, how to frame our needs, and where to find the right information. Most families don't have that. DAN exists because every family deserves the same starting point I had.'*
>
> — Beth Martinko, SDTA / Captain's View Advocacy

Josh is one of over 8,000 people currently enrolled in Self-Determination — less than 2% of the well over 450,000 Californians the Regional Center system serves, and growing. Not because they aren't eligible. Not because the program isn't right for them. Because they don't know, or because the path in is too hard to navigate alone.

Josh's journey didn't end with SDP. This year, Josh transitioned from conservatorship to Supported Decision-Making — a legal alternative that allows a person to keep their own rights while choosing trusted people to help them understand information and think through decisions. Most families navigating the Regional Center system have never heard of Supported Decision-Making, and most Regional Center coordinators was the only option. It isn't. DAN exists in part to make sure families know what their choices actually are — before they make decisions they can't easily undo.

The system tends to treat developmental disability as a fixed state — something to be managed, accommodated, stabilized. Josh's story is a reminder that it isn't. He's a published author, a voice-over artist, and now someone who has reclaimed his own legal decision-making rights. He keeps growing. The people this system serves keep growing.

SDP gave Josh control over his own services. Supported Decision-Making gave him back his rights and a trusted circle of people who help him think through decisions. Together, they did something that no single service or program could do alone: they future-proofed his life.

When Josh loses his mom someday, he will miss her. But his life — his independence, his support circle, his ability to direct his own services and make his own decisions — will continue. That is what good navigation through this system can do for a family. Not just solve the problem in front of you, but set up the person you love to keep thriving when you are no longer there to advocate for them.

That is what DAN is for. Not just the crisis at 2am. The long game.

That growth should be celebrated — not penalized. One of the quieter fears families carry is that sharing a success will trigger a service reduction if he learned to cook, maybe he doesn't need support anymore. It's a reasonable fear, learned from experience. But growth doesn't mean less support — it means better support. The IPP is supposed to be a living plan that evolves with the person, not a ceiling that lowers as accomplishments mount.

DAN is built on the belief that the right navigation at the right time doesn't just help families survive the system — it helps them imagine what's next, advocate for services that match who their family member is becoming, and share their wins without fear.

But the SDP gap is only one part of this story.

THE PROBLEM
The gap is everywhere — not just in SDP and SDM

California's developmental disability system, built on the landmark Lanterman Act of 1969, was designed to guarantee services as a right — not a privilege. The law is clear: Regional Center clients are entitled to the services they need to live full, independent lives in their communities. The system was built on a promise of equity.

The reality looks different.

430K+
Californians currently served by the Regional Center system
California Department of Developmental Services, 2026

~50%
Per-capita spending gap — people of color receive roughly half what white clients receive
Disability Rights California, 2021

17 of 21
Regional Centers where the spending gap between Latinx and white children worsened over 6 years despite $800M invested to fix it
Public Counsel 2022

Some have suggested that the service gap reflects cultural preferences — that families in communities of color choose to keep their family member at home, and that fewer services simply reflect that choice. This framing gets the causality backwards. A person living at home with family doesn't need fewer services. Independent Living Services teach skills. Supported Living Services provide ongoing support in someone's own home. A person who needs help with cooking, personal care, or medication management has that need regardless of whether they live with family or alone. But SLS — the service designed to meet that ongoing need — is available to people living independently. People living at home with family are systematically offered skill-building instead of support. The gap isn't a preference. It's a structural inequity built into how services are offered.

The gap inside the Self-Determination Program tells the same story in sharper relief. DDS's own October 2024 data shows that Hispanic clients make up 41% of the total Regional Center population — but only 19% of SDP participants. White clients are 27% of the RC population but 44% of SDP. Spanish-speakers are 19% of all RC clients but just 8% of SDP participants. The program is available to everyone. The knowledge and navigation required to get there is not.

The disparities are documented, persistent, and structural. They show up in who gets services, how much they get, and how effectively families can participate in their own planning. Families who know how to navigate the system — who understand what to ask for, how to frame their needs, and what information to bring to an IPP meeting — are better positioned to get the services that are right for them. Families who don't have that knowledge don't even know what they're missing.

Regional Centers want to serve families well. The challenge is that the system is complex, and the gap between what families are entitled to and what they know how to ask for is often wide. Service coordinators carry heavy caseloads. Families arrive at meetings underprepared through no fault of their own. DAN is designed to close that gap — not by creating friction, but by helping families show up informed, ask better questions, and participate more fully in their own planning.

And the gap starts before you even enter the system. Families who don't know Regional Center exists, who don't know they qualify, who face language or cultural barriers — they aren't counted in any of these statistics. They're simply not there.

The state's own oversight bodies have named this gap directly. The Little Hoover Commission — California's independent government oversight agency — reviewed the developmental disability system and called for urgent action to address longstanding inequities that make it easier for some families to access services than others. At a January 2020 follow-up hearing, community members confirmed these challenges remain. Families described the heavy burden of navigating the system on their own, and witnesses noted that even when needs are formally identified, services are not consistently implemented. The State Council on Developmental Disabilities has made reducing complexity in the service delivery system and ensuring successful SDP implementation explicit priorities for 2025–26. DAN is built in direct response to those gaps.

This is what DAN is built to fix. Not by replacing the people and organizations doing this work — advocates, Independent Facilitators, service coordinators, disability rights organizations — but by making sure that every family arrives at those conversations prepared. Knowing what their situation is, what questions to ask, and what information to bring with them.

THE SOLUTION
What DAN does — and doesn't do

DAN's first move is to listen. Before it explains anything, it asks one question: what's actually going on for your family right now? The answer to that question shapes everything that follows — because the same system looks completely different depending on where you are in it.

That design choice isn't arbitrary. Before building DAN, we reviewed how similar navigation and guidance programs have been designed in other high-stakes fields — healthcare, legal services, and process improvement — and identified the same pattern in programs that work well: ask before you explain, ground responses in a specific and vetted knowledge base, and close every interaction with a clear next step. DAN was built to meet that standard.

DAN is built for the self-advocate and everyone in their circle of support — family members, caregivers, and trusted people who show up when it matters. It meets them where you are, right now, in the middle of whatever is happening. Not with a manual to read later. With education about what the system says your rights are, real help understanding what's going on in your situation, and a clear next step you can take today.

- **Rights and policy translation**
  The Lanterman Act, DDS Directives, and Regional Center purchase of service policies explained in plain language — with the source cited, so families know where the information comes from and can point to it in their own conversations.
- **Situation recognition**
  DAN recognizes the most common situations families find themselves in — not knowing what services are available, uncertainty about how to frame a request, not knowing what information to bring to an IPP meeting — and helps families understand what's happening and what to ask for next.
- **Next step guidance**
  From understanding how to prepare for an IPP meeting to knowing when and how to request a supervisor conversation or a formal review — DAN helps families understand what options exist and how to use them, step by step.
- **SDP orientation and readiness**
  Helping families understand what Self-Determination actually is, what the enrollment path looks like, and whether it might be right for them — before they ever talk to anyone at their Regional Center.
- **IF handoff**
  When a situation is complex enough to need a professional advocate or Independent Facilitator, DAN doesn't just say "go find one." It creates a plain-language summary of where the family is and what they've tried, so the first conversation with an IF starts informed.
- **Always available**
  No appointment. No cost. No waiting until Monday morning. Families can access DAN whenever they need it — at 2am, in Spanish, in the middle of an IPP meeting, anywhere.

What DAN is not: DAN never gives legal advice, predicts outcomes, or inflames difficult relationships. When a situation calls for a lawyer, an IF, or another resource, DAN says so clearly and helps families get there.

You own your journey. DAN is designed so you stay in complete control of your own information. No account. No login. Nothing stored anywhere. What you share in a session stays in that session — when you close the window, it's gone. If you come back with a follow-up, you decide whether to share your prior session. People navigating the Regional Center system have often experienced their information being used in ways they didn't expect. DAN works the other way.

HOW IT WAS BUILT
Co-developed, not consulted

DAN's knowledge base is grounded in the Lanterman Act, DDS Directives, Regional Center purchase of service standards, and frontline advocacy experience — the core rights and policy layer that applies across all 21 Regional Centers. It was built and validated by people who work inside the Regional Center system every day, not by researchers reading about it from the outside. The DAN Advisory Board brings together Independent Facilitators, family advocates, and people with lived IDD experience whose practical knowledge shapes every pattern DAN recognizes and every piece of guidance it gives. When written policy and real-world IEC behavior diverge — and they often do — the Advisory Board is how DAN knows the difference.

Self-advocates are advisory council members. Their lived experience doesn't just inform DAN — it shapes how it speaks and what it prioritizes. Pilot families are co-developers. Working Independent Facilitators helped design the handoff pattern so that when DAN refers a family to an IF, the summary it produces is something an IF actually finds useful.

This is not a technology solution built by people who read reports about disability services. It's built by and with people whom the system is designed to serve.

WHAT IT LOOKS LIKE
DAN in action

This is a representative example of a DAN conversation — the kind that happens every day, at all hours, for families who are trying to figure out where to start. Notice that DAN's first job isn't to give information. It's to understand the situation. Then it helps.

This is a representative example. DAN's actual responses are drawn from its knowledge base, described in the section above.

WHERE WE ARE
Pilot — all 21 Regional Centers

DAN launched in March 2026 as DAN Light — a Pilot phase available in English and Spanish, built to validate that the guidance is accurate and the voice lands well before addressing six finalized stuck points in the Regional Center system: "That's a preference, not a need", "We're waiting for an answer", "My SDP plan is pending and things aren't in place", SDP Spending Plan problems, "That goal isn't in the IPP", and "There's a generic resource for that." Everything is designed to expand: as DAN grows, the core navigation logic and knowledge base stay the same while RC-specific details and additional expert advisory guidance layer in.

The roadmap is straightforward. The Pilot is proof of concept with real experiences — in English and Spanish. Phase 1 expands to five or more Regional Centers through the SDTA platform, with Spanish validation by bilingual community members and additional RC-specific guidance as needed. Phase 2 reaches all 21 RCs statewide, with Vietnamese, Korean, and additional language support — because the knowledge gap is deepest in communities where the system was never designed with you in mind. The pace of expansion is dependent on additional funding, which we will be seeking.

DAN will generate something that doesn't currently exist at scale: aggregate, anonymous data on what families are actually struggling with — by topic, by stage, by how often situations escalate to formal appeals. Not case files. Patterns. What kinds of service requests are most commonly denied. Where families get stuck most often. How that changes as the system evolves. That data belongs to the field — to advocates, policymakers, researchers, and the state agencies working to make the system more equitable. It is a byproduct of DAN doing its job, and it becomes more valuable the more families DAN reaches.

SDTA is a 501(c)(3) nonprofit. The mission is access — and access only works if there is no price of admission.

AN INVITATION
The circle DAN needs around it

DAN doesn't grow or improve by itself. It gets better when the right people bring their expertise, their experience, and their networks to it. The circle below describes who we're looking for — not as a formal structure, but as a description of the people and organizations whose involvement makes DAN more accurate, more trusted, and more useful.

AT THE CENTER
Self-advocates and family members — the people DAN is built for. People DAN puts self-advocates who have navigated this system and want to help others do the same. Their experiences, feedback, and stories are DAN's most important quality check. If DAN doesn't reflect what actually happens, it needs to change.

INDEPENDENT FACILITATORS AND ADVOCATES
Working IFs and disability rights advocates who understand the system from the inside. They validate DAN's guidance, help shape the handoff pattern, and ensure that the families DAN refers to them arrive ready for a productive first conversation.

POLICY AND SYSTEMS LEADERS
People working at the state level — at DDS, SCDD, regional centers, and advocacy organizations — who understand where the systemic structural problems live and how technology like DAN can connect to broader equity work already underway.

ORGANIZATIONS IMPROVING FRONT-DOOR ACCESS
SDP Local Advisory Committees, agencies, nonprofits, and companies whose mission includes reducing barriers to disability services — whether through technology, outreach, training, or direct service. DAN is most effective when it's connected to the full ecosystem working together. We actively seek your assistance in funding.

If you see yourself in one of these circles — if you have lived experience, advocacy expertise, policy influence, or organizational capacity to bring — we'd love to hear from you.

Beth Martinko · Program Architect, DAN · Founder, Captain's View Advocacy
Self Determination Tech Alliance (SDTA) is a 501(c)(3) nonprofit. DAN is free to families. Always.

Statistics sourced from California Department of Developmental Services, Disability Rights California, and Public Counsel (2022–2025). SDP enrollment and demographic data from DDS SDP Statewide Demographics Report, October 2024.