

From the Self-Advocate and Family Point of View

What we're hearing about the Regional Center system

An SDTA Report · March–May 2026

This report is published in English and Spanish with full parity.

About

This is the Self-Determination Tech Alliance's first quarterly read of what self-advocates and family members are telling us about California's Regional Center system — in their own words, from their own seat.

We listened three ways this quarter: a **community survey**, **written feedback gathered at a Disability Voices United (DVU) SDP Connect meeting in April** on recent SDP directives, and **DAN** — our free, bilingual navigation program used by families across the state.

One thing said plainly: this is what we heard from the people who engaged with us this quarter. The people who reach us are often navigating something hard. That is the point. Everything below is reported anonymously and in aggregate; no individual's story is identifiable.

The report has three parts. **Part One is what we heard, reported as we heard it. Part Two is our point of view, which follows from it. Part Three is how we listened — and how we will sharpen the picture next quarter.**

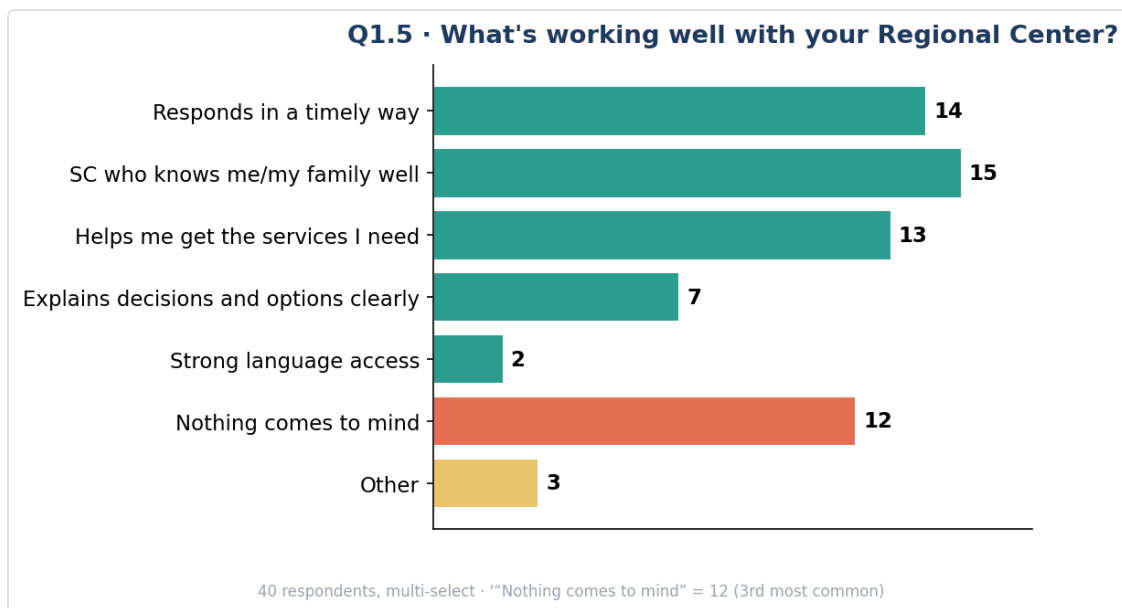
Part One — What we heard

1. What families value

The first thing worth saying is what's working — because the community was clear about it, and because it points the way forward.

The two things families named most often as strengths were **relational**: a service coordinator **who knows their family**, and a coordinator who **responds in a timely way**. When the system works for a family, it is almost always because of a person — a coordinator who is present, responsive, and consistent.

"I am lucky that my participant choice managers are awesome." — Redwood Coast, Independent Facilitator



Survey responses: what's working well with your Regional Center.

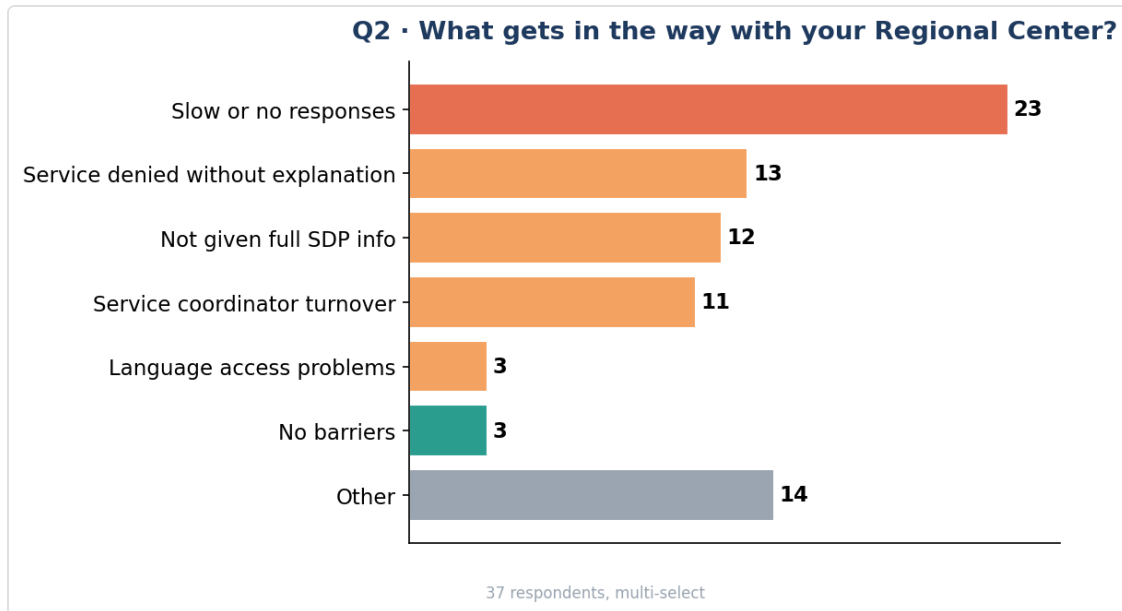
Honesty requires one note alongside the praise: the third-most-common answer to "what's working" was, in effect, *nothing comes to mind*. The good experience is real, but it is not universal — which is what the rest of this section is about.

Families were equally clear when DDS got something right at the policy level: the directive strengthening **client-information privacy** drew direct appreciation (Section 3).

The relationship families value most is a steady, responsive coordinator. That is the model. Much of what follows is about what gets in its way.

2. The challenges families named

Four themes came through consistently.



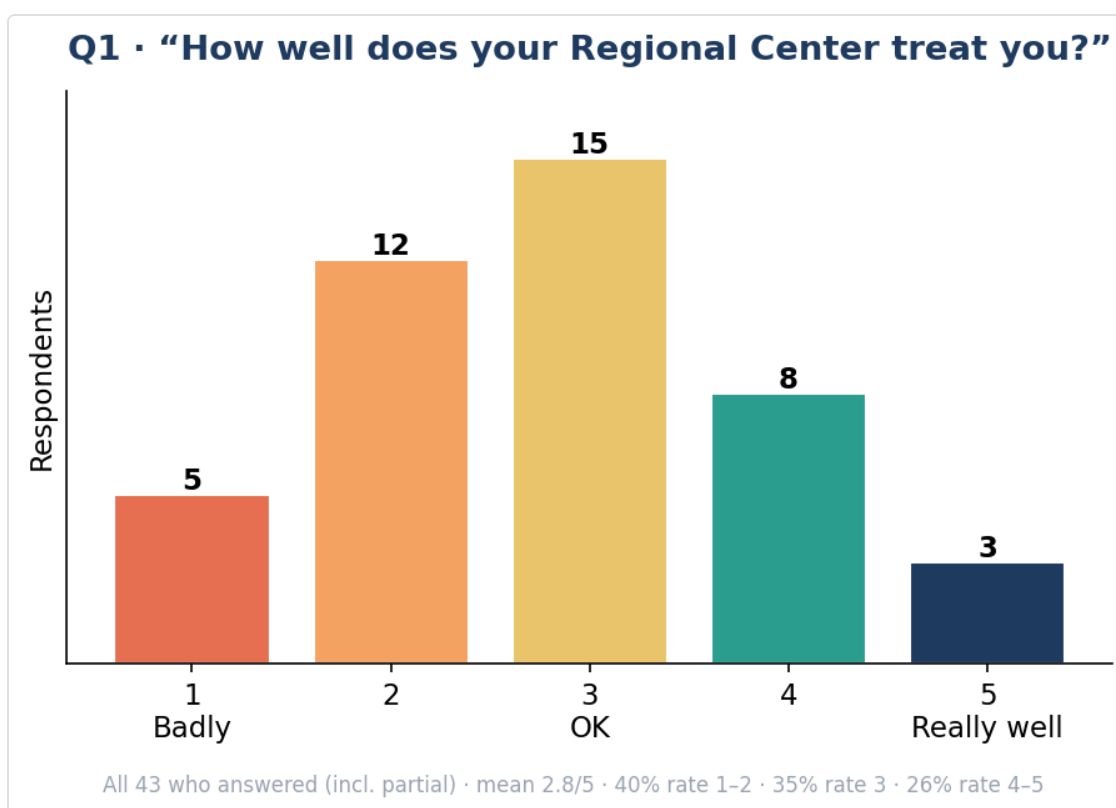
Survey responses: what gets in the way with your Regional Center.

Communication, and closing the loop. The most common difficulty families describe is waiting — and not hearing back. Slow or no response was the single most-named barrier in the survey. In DAN, the most common sticking point in a conversation is a family **asking the same question several different ways** — the same gap, seen from another angle. What's missing is clear, written communication; its absence leaves families in uncertainty.

"My service coordinator is awesome, but sometimes the people that help get stuff changed take forever to respond or get stuff done or even answer questions. They eventually get stuff done, but it takes a long time." — Inland, self-advocate

"Lo que más me ayudaría sería recibir respuestas más claras y oportunas, especialmente por escrito... con explicaciones claras sobre qué documentos se necesitan, cuánto tiempo tomará la decisión y qué opciones tenemos si un servicio es negado o reducido." — San Andreas, family member ("What would help me most would be clearer and more timely answers — especially in writing — with clear explanations of what documents are needed, how long the decision will take, and what options we have if a service is denied or reduced.")

Consistency, and accountability. Families describe the same rules landing very differently depending on where they live and whom they work with. On a five-point scale, families rated their Regional Center experience **2.8** on average — a system that works well for some and poorly for others.



Survey responses: how well does your Regional Center treat you? (1-5)

"I'm hearing things approved at other regional centers that won't fly at my own." — RCOC "The rules of SDP should not differ by RC location or service coordinator." — Redwood Coast "Oversight with real accountability that is consistent across all Regional Centers. Why develop an IPP if the Regional Center has no obligation or accountability to implement it?" — RCOC

Some described being told no without an explanation; others, in Spanish, simply asked that the answer be yes more often: *"Que aprueben terapias y no pongan barreras."* — Kern (*"Approve therapies and don't put up barriers."*)

The Self-Determination Program (SDP) is hard to see into. Families describe SDP as difficult to navigate — getting clear information, managing spending-plan updates, and handling transitions. Not being given full information about SDP was among the most-named barriers, and SDP is one of the most common things people bring to DAN.

"Que tengan más personal para procesos de transición a SDP. Revisión de plan de gastos: en días tardan meses. Procesos más rápidos en actualizaciones de planes de gastos." — Inland, family member (*"More staff for the transition into SDP. Spending-plan reviews that should take days take months. Faster processes for spending-plan updates."*)

Staffing and turnover — the root of much of the above. When the relationship families prize most breaks down, turnover is often why. Families describe feeling like a case number rather than a

person, with rushed reviews and gaps when a coordinator leaves. Their recommendations were striking for how much they took the coordinator's side:

"Increase service-coordinator positions to decrease response time and reduce burnout." — Inland
"Reduce caseloads for service coordinators — it will help everyone across the board." — Harbor
"El trato más humano y cordial al cliente. Que las coordinadoras tengan más chance de trabajar con uno y dar más recursos." — Lanterman, family member ("More humane and cordial treatment of the client — and coordinators with more chance to work with you and provide more resources.")

The communication gap families feel and the staffing pressure coordinators carry are the same problem, one step apart.

3. How the community read recent SDP directives

Community members reviewed recent SDP directives against the five principles of self-determination — Freedom, Authority, Support, Responsibility, and Confirmation. The read was discerning: directives credited where they protect families, flagged where they move authority away from the community.

🟢 **Welcomed — Client-information privacy.** A protection that strengthens families' rights, with the burden placed on the system rather than the person. *"Appreciate this, especially in these turbulent times, that you are protecting our privacy."*

🟢 **Welcomed — Initial budgets (AB 143).** Read as a community-won win: the budget approach reflects unmet need, and the community's voice shows through. Where it constrains, families recognized the constraint as coming from statute, not from DDS's discretion.

🟡 **Mixed — Orientation update.** Families welcomed the directive's language-access expansion. Their concern was not that orientation is being standardized, but that its delivery is being **centralized to a single statewide provider** — a shift away from local control that retires the community-based orientation providers (Regional Center, parent-to-parent, and community-hosted) who had been the cultural-trust bridge for the very families the language expansion is meant to serve.

"Cambie que solo SCDD esté dando las orientaciones; es una gran barrera, no tiene suficiente personal." — Inland, family member ("Change the fact that only SCDD gives the orientations — it's a big barrier; they don't have enough staff.")

🟡 **Mixed — FMS vendorization.** Vetting Financial Management Service entities is reasonable on its face; the concern families raised is that they had no role in setting the criteria those entities are judged by.

🔴 **Flagged — LVAC defunding.** The directives that move funding authority away from Local Volunteer Advisory Committees and back to Regional Centers drew the clearest, most consistent

concern.

"DDS took away authority from the LVACs... by allowing Regional Centers the final determination, they removed our voice in a material way. The community views this as a loss of trust." "Las directivas que están sacando están a favor del centro regional, no apoyan a los clientes." — Inland, family member ("The directives they are issuing favor the regional center; they don't support the clients.")

The principles families most often saw harmed were **Authority, Freedom, and Confirmation** — the last being the simple fact that no one measures whether a change actually worked.

The same community that thanks DDS for protecting privacy flags LVAC defunding. The signal is specific. It is not reflexive.

4. What DAN is seeing

Reach. DAN is a free, anonymous, bilingual navigation program. Over its first 91 days it logged **910 real sessions**, used in **20 of California's 21 Regional Center areas**, with **55% of use outside business hours** — the evenings and weekends a staffed Regional Center structurally can't cover. DAN runs fully in Spanish as well as English, and it is reaching the Latino community the system has long underserved: among the sessions where a family chose to share their race or ethnicity, **more than one in five (22%) identified as Hispanic or Latino** — likely an undercount, because the single-select question forces "Hispanic" to compete with race categories. Of the answers families rated, **79% were marked helpful** — and every Not Helpful rating with a specific issue is reviewed, the great majority resolved within days.

What people bring. The most common reasons people come are **a service (67%), the Self-Determination Program (59%), and an IPP (52%)**. Underneath, in roughly **a third** of the sessions DAN could read, the family had already hit a denial, a Notice of Action, or a no-response — even when they arrived with a general question. People rarely say "my rights are at risk." They say "I'm trying to get something," and a clock is often already running that they can't see.

How deeply families engage. These are not quick searches. Of the sessions where we measured length, **nine in ten ran to three exchanges or more, and nearly half went well past six** — and the deeper a conversation goes, the more often it ends with the family holding a concrete next step. Over the quarter, that resolution rate has climbed from **40% to 63%**.

Part Two — Our point of view

Part One is the community's voice. What follows is SDTA's reading of it.

5. What the three sources agree on

A survey, a directive review, and an anonymous record of 910 navigation sessions are three very different instruments, gathered from three different groups of people. They converge on the same few things:

- **A timely, clear response, and a closed loop.**
- **The same rules, applied consistently, wherever you live.**
- **Real authority over your own spending plan.**

And one thing none of the system's existing channels can see: **the silence that never becomes a formal "no."** A non-response triggers no Notice of Action, so no appeal clock starts, so it appears in no oversight data. It is, today, structurally invisible — and it is one of the most common things families describe. In the sessions DAN could read, roughly one in seven involved a family waiting on an answer that never came.

The convergence is the signal.

6. A Call to Action: Invest in the Frontline

Based on what families told us, frontline human interaction is the single most valuable place to invest.

1. Set, publish, and report on response timelines. The system — DDS and the Regional Centers together — commits publicly to clear, consistent timelines for responding to inquiries and service requests — and measure and report whether those timelines are actually met. (Families named *Confirmation* — whether a change is ever measured — as a principle the system most often misses.)

2. Move standard decisions closer to families. Empower individual service coordinators to approve standard, well-defined service requests against clear competencies and regulations — reducing the layers of approval that, in practice, mostly add delay.

3. Keep communication human. Plain, common-sense language; families treated as individuals, not case numbers; and continuity with a coordinator who stays long enough to know them.

4. Help families express their need in a way that's easy to say yes to. A request that is clear, specific, and well-supported is easier for a coordinator to grant — and more likely to succeed.

Families asked for the first of these in their own words:

"...if there were a portal site or another system where families could track the progress of requested services. Currently, families often have to repeatedly contact service coordinators to ask about updates." — RCOC, family member

For the system's service delivery, the most important lever is not more technology. It is investing in the people who interface with families every day. You cannot bolt software onto an unresponsive system and call it fixed.

7. The gap technology should fill — and how DAN is meeting the need

There is a second problem, and it is structural rather than about service delivery.

California's developmental-disability system is **decentralized by design** — which keeps services local, a real strength — but it leaves families navigating **21 independent Regional Centers, disconnected websites, and inconsistent terminology for the same concepts, largely on their own**. What the system has never had is an **advocacy and navigation layer**: somewhere a family can get real-time, situation-specific help making sense of all of it.

That is the unmet need, stated plainly: **no program — human or software — sits with a family through an intensive, real-time, back-and-forth on their specific situation, synthesizes the best of what the entire state system offers, and hands them grounded draft emails or talking points to get unstuck.**

"Muchas veces los padres tenemos que buscar información por nuestra cuenta, esperar mucho tiempo por respuestas o insistir para recibir servicios... sin que las familias tengan que luchar tanto para obtenerlos." — San Andreas, family member ("Many times we parents have to look for information on our own, wait a long time for answers, or keep insisting to get the services our children need — without families having to fight so hard to get them.")

This is the need DAN was built to meet. DAN doesn't just answer questions. It asks the family the right ones, surfaces the information that strengthens their specific request, and helps them turn a vague worry into a clear, well-supported ask — one that is more likely to succeed. It is a real sounding board and coaching tuned to a family's own situation, not a list of links. Families describe the result in almost the same words again and again: *it sounded like an advocate wrote it for me*. One family at San Andreas Regional Center put it this way:

"I just used DAN today, and in 30 minutes it unstuck a conversation I'd been having with my regional center and SDP that had gone on for months."

Until now, that kind of advocacy input was available only to a family who could find — and afford — an advocate. **This is, fundamentally, an equity tool.** The families who can least afford a private

advocate — disproportionately the same communities the disparity data has long shown to be underserved, including the Latino families who make up more than a fifth of DAN's reach — are exactly the families who most need one. DAN provides that advocacy input to everyone, free, with no restrictions. It puts within reach of every family the kind of help that, until now, only some could buy.

It helps the Regional Center, too. A request that arrives clearer, better organized, and better documented is easier for a coordinator to act on; when families come in better prepared, the back-and-forth shrinks for everyone. The responsibility to inform and guide families still rests, properly, with the Regional Center — DAN is a bridge over a gap that shouldn't exist, not a substitute for the duty to close it.

The community has begun to validate DAN as the advocacy layer it was missing: 910 sessions across nearly every Regional Center area, nearly four in five rated answers marked helpful, families returning, and one naming the need before they had a word for it:

"Someone like an advocate or something like DAN that can provide clarity on subjective matters that RC keeps rejecting me on." — East Bay

Two gaps, two answers: the system's **service delivery** needs people, not software. Its **missing advocacy layer** needs exactly the kind of technology DAN provides.

Part Three — How we listened, and how we will improve

8. How we listened

- **Community survey** — an open survey representing a blend of community voices: a first wave of **45 responses (including partial responses), 12 of them (27%) in Spanish**, March–May 2026. We report the distribution of what people said, not a statewide rate.
- **Directive feedback** — written input gathered at an April DVU SDP Connect meeting, reinforcing generally recognized community perceptions (treated in Section 3).
- **DAN** — 910 anonymous navigation sessions; reasons read from the conversations themselves; reported only in summary, never per person. SDTA does not share raw transcripts or row-level data with anyone.

9. How we will improve

This is a first read, and we are already building toward a sharper one. Over the coming quarter, DAN will capture more of what families experience — always anonymously, always in summary, never tied to a person. Specifically, we are adding the ability to see:

- **When a family is told no** — what was denied, the reason they were given, and whether a formal Notice of Action was issued (the step that begins a family's right to appeal).
- **What families are waiting on, and for how long** — the silence that never becomes a formal "no," made visible and, for the first time, countable.
- **Whether a family learned of a right they didn't know they had** — a measure of the gap between what families are owed and what they know to ask for.
- **Which specific services are most often at issue** — so patterns can be read service by service, not just in general.
- **How a family arrives, and how they leave** — whether a conversation moves someone from stuck and overwhelmed to clear and ready to act.

These are exactly the things the system's existing channels cannot see today. Capturing them is how next quarter's report moves from *what families are asking about* to *what is actually happening to them* — the fuller picture the community and DDS both need. We share the method openly and improve it in the open. That is what it means for DAN to be the community's instrument of record.

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