



Project RDAC

Resources and Supports

for State Rare Disease Advisory Councils (RDACs)

National Organization for Rare Disorders (NORD®)



Defining a Rare Disease Advisory Council

National Organization for Rare Disorders' (NORD®) Considerations for NORD Project RDAC Programming and State Report Card® Grading

NORD is committed to our NORD® State Report Card® and Project RDAC initiatives, including our Rare Disease Advisory Council (RDAC) member portal, monthly RDAC communications, shared resources, and our annual in-person meeting. We want to be transparent with council leadership about the criteria NORD uses to determine which state bodies qualify as an RDAC for these purposes.

THE CORE STANDARD: EMBEDDED WITHIN STATE GOVERNMENT

For NORD's purposes, a council must be structurally embedded within, or have a direct, ongoing connection to, state government.

NORD recognizes there are multiple legitimate routes to RDAC status, in addition to a standalone legislative act. Examples of RDAC-establishing acts of state government NORD has seen and could reasonably expect to see include but are not limited to:

- Legislative act, bill, or resolution
- Executive Order
- Administrative Agency Action
- Appropriations-Driven Efforts
- Subunit of an Existing Statutory Board, Commission, or Agency
- Non-profit Operating Under State Grant with Formal Relationship to State Agency
- Procurement or Contract with State Agency
- Memorandum of Understanding (MOU) with a State Entity

RDACs maintain access to NORD Project RDAC resources and supports as long as the formal relationship with state government remains in place.

For more information on how NORD defines RDACs, explore NORD's Project RDAC [website](#) or contact NORD Policy staff at policy@rarediseases.org.

Project RDAC Impact

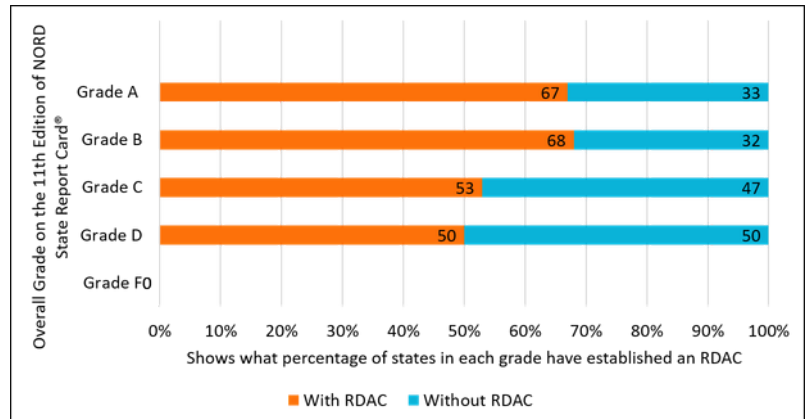
THE RDAC EFFECT: BETTER POLICIES, BETTER GRADES

Statistically significant ($p=0.002$)

First-Ever Statistical Analysis of RDAC Effectiveness (2025)

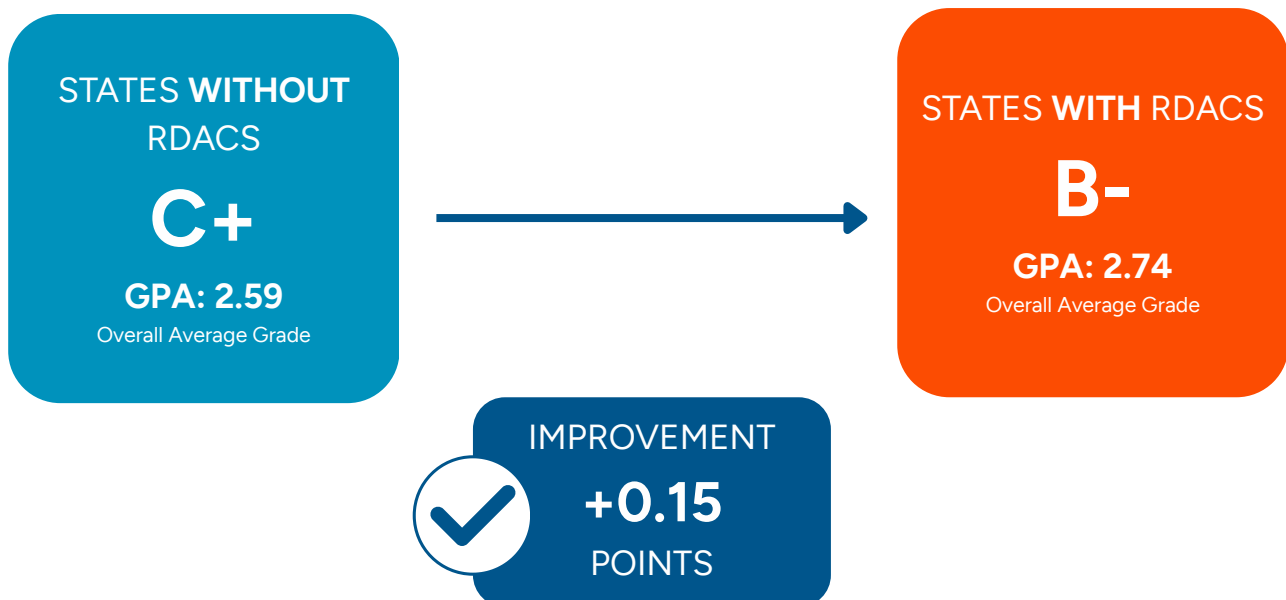
NORD conducted a quantitative analysis of State Report Card® data to measure RDAC impact on state rare disease policy.

Methodology: Statistical analysis measuring policy improvements while controlling for the RDAC grade itself.



★ **KEY FINDING #1: Top-Performing States Have RDACs**
~70% of top-performing states have established RDACs

★ **KEY FINDING #2: RDACs Drive Measurable Policy Improvement**
States with RDACs show statistically significant improvements in rare disease policies



Impact Stories



MINNESOTA: POLICY INNOVATION WITH NATIONAL POTENTIAL

The Minnesota RDAC developed groundbreaking "Network Access" legislation which fundamentally eliminates the concept of out-of-network care for rare and undiagnosed patients.



MISSOURI: DIRECT IMPACT ON MEDICATION ACCESS

Missouri's RDAC identified that Medicaid approval for Zolgensma - a gene therapy for children with spinal muscular atrophy - was taking years. Through expert recommendations, the RDAC helped expedite approval processes.



FLORIDA: ADVANCING RESEARCH FUNDING

Florida's RDAC reviews pediatric rare disease research grants, ensuring funding reaches impactful projects and bringing the community perspective into research prioritization.



TENNESSEE: AWARENESS CAMPAIGNS

Tennessee's RDAC secured Rare Disease Day® billboard placement across downtown Nashville, creating statewide visibility and raising awareness about the diagnostic odyssey and available resources.



MISSISSIPPI: BUILDING FOUNDATION IN YEAR ONE

In its first year, Mississippi's RDAC was already tasked by the legislature to conduct a study on alternative funding programs - demonstrating that even new councils are immediately recognized as valuable by lawmakers.



VIRGINIA: BREAKING NEW GROUND IN RDAC RESEARCH CAPACITY

Virginia's RDAC became the first to secure IRB approval for their survey. At NORD's 3rd Annual National RDAC Meeting they presented on how they navigated the process, providing a roadmap for other councils to follow suit.

NORD Project RDAC Resources and Supports

NORD is working to establish Rare Disease Advisory Councils in every state. Whether you're a newly operational council or well-established, these resources are available to you.



Council Operations Support

- Access to model survey for council use.
- Connection to peer councils for operational questions & solution-building.
- Access best practices from councils nationwide.
- Access to Coalition, Legislative, and Implementation toolkits.
- Access to RDAC Member Portal with discussion forum & downloadable resources.
- Receive monthly bulletins with legislative updates, best practices, and resources. Example topics to date: Budget requests, Joining Sign-Ons, Housing Entity Case Studies.



Convene & Connect With Other Councils

- **Annual In-Person Meeting:** 2-day fall gathering with 40-60+ RDAC members across the country. Keynotes, panels, breakouts and networking. Complimentary NORD Breakthrough Summit® access and travel/lodging covered for 2 council representatives per state.
- **Virtual RDAC Showcases:** Council-led presentations open to all RDACs, with one-pager takeaways for replication. Example topics to date: Survey IRB Approval, Policy Strategy, Council Preservation.
- **NORD Community Engagement events:** NORD involves RDACs in broader engagement initiatives wherever possible. Examples include RDAC tabling at Living Rare, Living Stronger® events, member participation in planning committees, and invitations to local NORD events.



State-Specific Data on the Patient and Provider Experience

- NORD RareCare® Patient Assistance Program support and data
- Access to aggregated state-specific patient data: call volume, top diseases, barriers reported, types of assistance requested, age/demographic profile.
- Receive data on where your state's patients travel for care and gaps in specialty capacity.
- Direct consultation with NORD's Patient Services team on patient experiences, barriers, solutions, and equity issues.
- Referral line call center: English and Spanish-language direct patient and caregiver support.



NORD Rare Disease Centers of Excellence Network

- Access to clinical experts and providers to fill council vacancies.
- Access to clinical experts and providers to consult on rare disease care delivery.
- Arrange tours of the State's Rare Disease Center of Excellence facility(ies).
- Access NORD's database of 10,200+ rare diseases.



Policy Analysis & Guidance

- Presentations rare disease policy analysis, landscape and data through NORD State Report Card®.
- Get analysis of bills moving in your state that NORD is tracking.
- Receive proactive alerts on bills NORD is monitoring in your state.
- Get alerts on regulatory developments with briefing materials to support your engagement.
- Assistance developing and drafting policy recommendations for council reports.
- Access to model policies for introduction in state legislatures or adoption by state agencies.
- Connection to federal experts (FDA, NIH, OOPD) and congressional staff for RDAC meetings, events, roundtables, and learning opportunities.
- Guidance on engaging state Medicaid, insurance regulators, and health departments, including toolkit resources.



Communication & Visibility

- NORD will share your work through our website, newsletters (500k+ subscribers), social media (400k+ followers), and our national and state-specific distribution lists. NORD can share:
- Council announcements and meeting notices
- Council posts and thought leadership
- Reports and policy recommendations
- Research and data published
- Council vacancies
- Council events
- Population survey
- Guest blog posts
- Media relations support: pitching stories, connections to letters, and letter to the editor

NORD can also provide support with media relations (pitching stories, connections to reports, and letters to the editor), and often provide promotional items (notepads, stickers, pens, other branded items) for RDAC events and outreach.



Council Defense & Advocacy

- Council Defense: If facing threats NORD organizes a coalition of peer RDACs and community stakeholders, mobilizes sign-on letters, testimony, and direct advocacy with your state government.
- NORD Advocacy Integration: RDACs are integrated into NORD's state policy work; we consistently advocate for council involvement in state policy decisions.
- Annual RDAC Stakeholder Webinar: NORD hosts a webinar for the broader rare community calling attention to your achievements and impact from the last year.
- NORD policy staff educate lawmakers about your council and encourage legislative consultation.
- Receive bill drafting support and advocacy for council reorganization, funding, or optimization efforts.



Rare Disease Day® Support

- Promote council Rare Disease Day events through NORD channels.
- Access to Rare Disease Day materials and promotional items.
- Access to toolkits for securing government proclamations and resolutions.

NORD is committed to providing these resources and supports to state RDACs. Offerings may evolve as councils' needs change and as we learn what works best.

Getting Started

NORD is always available to provide any of the NORD Project RDAC Resources and Supports at any stage of an RDAC's life. RDAC members can receive any of the resources listed above by contacting rdacsupport@rarediseases.org. To enjoy the full benefits of Project RDAC, receive regular communications from NORD, and access NORD's RDAC materials, follow these steps:

- 1 Email rdacsupport@rarediseases.org. In the email body, include the contact information of the RDAC administrator, chair, and/or vice chair.
- 2 Send public-facing RDAC contact and website to rdacsupport@rarediseases.org once available to be included in the RDAC Public Directory.
- 3 Follow NORD on social media:
 - a. [LinkedIn](#)
 - b. [Instagram](#)
 - c. [X.com \(Formerly known as Twitter\)](#)
 - d. [Facebook](#)
- 4 Share your RDAC membership on social media! Use "What my RDAC membership means to me" graphic and tag NORD.
- 5 Join the member portal.

ABOUT NATIONAL ORGANIZATION FOR RARE DISORDERS

Founded in 1983, the National Organization for Rare Disorders (NORD®) is a leading independent, nonpartisan, nonprofit and patient advocacy organization dedicated to improving the health and lives of over 30 million Americans living with rare diseases. In partnership with more than 350 disease-specific member patient organizations, NORD drives progress in rare disease research, care, and policy.

Learn more at rarediseases.org.