

REPRESENTATION MATTERS GUIDE

TALKING ABOUT THE BASICS

Diversity within the rare disease community means that some of us are experts and some of us are just learning and starting out—whether that’s in research and drug development or nonprofit governance to issues around diversity, equity and inclusion. In this section, we define important terms to set the foundation for this guide. The definitions listed below come from a variety of reputable sources including the Ford Foundation, the US Department of Justice, the US Food and Drug Administration, BoardSource, and more (see references, below).

Inclusiveness refers to behaviors and actions that create a culture of belonging and a sense of value for all who participate and contribute, while at the same time understanding no one person can or should be asked to represent their entire community (see tokenism).

Diversity is defined as the representation of all individual attributes and identities (race, ethnicity, gender, disability, sexual orientation, gender identity, national origin, tribe, caste, socio-economic status, thinking and communication styles, etc.), collectively and individually.

Equity and **Equality** have slightly different meanings. Equity refers to fairness and justice, and equality means providing the same to all. Equity takes into consideration that we do not all start from the same place and must acknowledge and adjust imbalances to ensure the fair treatment, equality of opportunity and equality of access to information and resources for all.

Multicultural Competency is a process of learning about and becoming allies with people from other cultures so we can broaden our own understanding and ability to participate in a multicultural process. The key elements to becoming more culturally competent are to respect the ways that others live and how they organize the world, and to be open to learning from them.

Implicit Bias, also known as unconscious or hidden bias, is a negative association that people unknowingly hold. These biases are expressed automatically, without conscious awareness. Many studies indicate that implicit biases affect individuals’ attitudes and actions, thus creating real-world implications, even though individuals may not even be aware that those biases exist within themselves.

Explicit Bias is the traditional conceptualization of bias. With explicit bias, individuals are aware of their prejudices and attitudes toward certain groups. Positive or negative preferences for a particular group are conscious. Overt racism and racist comments are examples of explicit biases.

Tokenism is defined as diversity without inclusion—a superficial effort to meet numerical diversity goals or create the appearance of diversity without making deeper, systemic changes to ensure equitable opportunities and treatment for all.

REFERENCES:

Beyond Political Correctness: Building a Diverse and Inclusive Board (BoardSource)

bit.ly/building-diverse-board

Equity (National Association of Colleges and Employers)

bit.ly/equity-definition

Racial Equity Tools Glossary (Racial Equity Tools)

bit.ly/racial-equity-glossary

Understanding Bias: A Resource Guide (US Department of Justice)

bit.ly/understanding-bias-resource-guide

Five Ways to Avoid Tokenism in Diversity & Inclusion Work (The Network)

bit.ly/avoid-tokenism

FDA Diversity and Inclusion Strategic Plan (US Food and Drug Administration)

bit.ly/FDA-DI-strategic-plan

Diversity, equity, and inclusion (Ford Foundation)

bit.ly/DEI-Ford-Foundation

BEING A CHAMPION WITHIN YOUR NONPROFIT

The responsibility of improving diversity, equity and inclusion (DEI) within your organization should not rest on one person alone. If you have a structure that includes a human resources staff member or consultant, then this individual has an important role to play in championing an environment to foster DEI in the organization. If your organization is all-volunteer, then your board of directors and the organization's leadership has a significant role to play to foster DEI. Regardless of the leadership role, there are many individuals involved in a rare disease nonprofit that can and should be effective champions for DEI. To support your success, here are some best practices when encouraging honest conversation with your peers:

- **Gather data:** To understand your organization's baseline for addressing DEI, efforts should be made to assess practices, policies, organizational structure, etc., to highlight where improvements can be made. If you are a leader, encourage your board of directors to include an in-depth analysis to recognize implicit biases and knowledge gaps in your current strategic plan. This assessment may require hiring external consultants to help identify these gaps. The Georgetown University National Center for Cultural Awareness provides resources to help. Part of their mission aims to increase the capacity of health care programs to design, implement and evaluate culturally and linguistically competent service delivery systems to address growing diversity and persistent disparities, and to promote health and mental health equity. They offer a free course, "[Conscious & Unconscious Biases in Health Care](#)," which you may consider in your work understanding biases in the organization.
- **Create a non-judgmental environment:** What does a safe environment look like in your organization? Are you and others you work with comfortable with getting uncomfortable? Conversations may bring up a host of emotions, including pain, defensiveness, trauma and guilt. Your entire organization can work together to create a safe space for acknowledging this. As an individual in your organization and workplace, you can ask non-threatening, open-ended questions to provoke dialogue, create a rapport and find common ground. This can also be helpful if there is a need to emphasize the practical reasons for focusing on diversity.
 - What does diversity mean to you?
 - Why does X researcher care about diversity?
 - Do you think our board would operate differently if the formal membership reflected the diversity of the community?

- **Provide examples:** Learn about and be prepared to share examples about when diversity has helped your organization (or how the lack of it has hurt your organization's opportunities). There may be individuals within your organization who are learning and who would benefit from understanding the specific impact on diversity work in your rare disease community.
- **Connect with others:** What can you learn from organizations who have successfully implemented diversity, equity and inclusion initiatives both internally as an organization and externally in the community? Understand what they did well and what could be improved. Reference these organizations to build your case. NORD conducted several webinars with rare disease leaders sharing their work on DEI campaigns; see reference list below to access this resource.
- **Know your audience:** Determine your audience's willingness to be open and listen to discussions on diversity, equity and inclusion. At best, you will encounter people who are open-minded, willing to learn and unafraid of difficult lessons. On the other hand, you may find some people who want to be allies but are resistant to change. Adjust your strategy accordingly.
- **Network with allies:** Your efforts are best spent with those who are willing to have a conversation. Be sure to continue to foster these relationships and learn and grow together.
- **Create a plan:** Ensure that your approach to improving DEI, internally within your organization and externally for your community, is both strategic and data-driven. Your plan should be based on your organization's strategic plan and assessment with measurable, attainable goals based on organizational capacity.
- **Take the time:** Understanding the complex issues around diversity in your workplace will not happen overnight. It takes time to understand colleagues who may experience the workplace differently than you—and it may take time for you to learn how to comfortably talk about your experiences in the workplace.

REFERENCES:

DEI Case Studies from NORD's Rare Cancer Coalition (NORD Webinar)

bit.ly/NORD-DEI-case-studies

Why Diversity Matters and How to Get There (Joan Garry Consulting)

bit.ly/why-diversity-matters-Joan-Garry

4 Steps for Bringing Up Equity and Inclusion At Your Nonprofit (Bloomerang)

bit.ly/equity-inclusion-nonprofit

Starting Your DEI Strategy (Brighter Strategies)

bit.ly/DEI-strategy

Conscious & Unconscious Biases in Health Care

(National Center for Cultural Competence at Georgetown University)

bit.ly/NCCC-bias

FOSTERING ORGANIZATIONAL COMMITMENT TO DIVERSITY, EQUITY & INCLUSION

“According to the 2014 US census, 73% of Americans are White, compared with 80% of board members, according to Leading with Intent survey respondents. Similarly, the US census reports that 12.7% of Americans are Black or African American. Only 9.9% of nonprofit board members, however, are Black or African American. Furthermore, 25% of all boards remain all White.”¹

Building an Equitable and Inclusive Board

Define Your Why

Before you tackle the question of how your organization can become more diverse, inclusive and equitable, it is important to ground your discussion in your *why*. With that foundation, you can best determine how you can better serve your community.

Here are a few ways that an inclusive board supports organizational success:

- Promote creativity and innovation through the exchange of diverse ideas and perspectives.
- Reduce blind spots that can negatively impact decisions made for the organization.
- Discuss diversity, equity and inclusion internally to discover unmet needs in your community.
- Your population is rare and small—shouldn't you find as many people as possible who are impacted? Where do they live? Who are they? Inclusion means you're engaging and reaching more people affected by the disease.
- Create an organization that is relevant and grounded by fostering inclusiveness.
- Recruit diverse medical and scientific leadership who expand diversity in research, natural history studies and clinical work.
- Attract diverse donors and grants from funders with an increasing focus on diversity.

Rare Spotlight: *Your organizational mission likely includes serving all patients affected by the disease. But are there segments within this population you are missing who are unintentionally excluded by your communications or outreach strategies? What about people without internet or computer access? What about people who have language barriers? What about rural patients who can't afford to travel to major cities for their care? What about urban patients who don't have insurance? What about adult patients who work or are too busy to be involved in your organization?*

Discussion and Reflection

Engaging your board in open and thoughtful discussion about diversity, equity and inclusion is an important and necessary step to make progress. Your board members may have different understandings of what diversity, equity and inclusion mean, so start your discussion by asking a few questions. Here are some examples:

- Are we focused on better understanding the community we serve by bringing diverse points of view, needs, feedback and priorities to our board discussions?
- Do we have potential blind spots that put us at risk of making decisions without fully understanding how these decisions may affect our community? How do we become cognizant of these blind spots?

¹ <https://boardsource.org/wp-content/uploads/2016/08/Race-Role-Board-Recruitment.pdf>

- What do you think someone would assume about the values of our organization solely by looking at the composition of our board? Is there a perspective lacking that could benefit the strategy and mission of the organization? This may be a challenging or uncomfortable conversation to have if your board is homogenous in some way; perhaps your board is predominantly one gender or race, or there are more medical professionals than patients. Talking about your board with a critical lens may cause individuals to become defensive, but the intention is to work towards a more inclusive board. To do that, certain truths must be discussed.
- What could focusing on diversity, inclusion and equity mean for our community and the work of our organization?
- Who else do we need in our networks to help us expand the community we serve?

Creating a Plan to Build a Diverse Board

Once your board reaches a shared understanding about the importance of prioritizing diversity, equity and inclusion, the next step is to develop a strategy for implementing these values within the boardroom. This will allow your organization to not only articulate DEI but also demonstrate its values.

To solidify your commitment and create a shared vision, it might be helpful to start with a case statement. This statement, which could also be used as a vision statement, will define and clarify your focus and goals to create meaningful change. It should capture the following information:

- Your definitions of inclusiveness and equity, should they differ from the definitions we provided at the start of this guide
- Data about your community
- A description of what the board will look or feel like once it's inclusive
- How inclusiveness relates to the board's ability to affect your organization's mission
- How you envision putting your commitment to diversity, equity and inclusion into action
- How you assess the progress you are making towards your goals of diversity, inclusion and equity
- What success looks and feels like

When forming your plan to create a diverse, inclusive and equitable board, be strategic:

- Create "SMART" goals that are Specific, Measurable, Achievable, Relevant and Timebound with associated objectives. This will help your board remain focused and accountable for the tasks they want to accomplish.
- Review the needs of your organization to identify which skills, networks or backgrounds are missing from your board. Ideal board composition considers not only diversity but also expertise and experience.
- Identify new ways to source candidates to avoid recruiting from the same networks. For example, think about asking your volunteer network for suggestions or contacting your community leaders or organizations that represent diverse groups.
- Consider improving your board by including a medical expert who has experience supporting diverse communities. There may be clinicians working at the frontlines of your community who would add value, experience and knowledge about equity concerns and ways to engage underserved communities.

For example, your goal could be to recruit, welcome and integrate three members whose voices and perspectives are currently underrepresented on the board—and to do so within the next two years. Associated tasks could include reviewing your organization’s needs within the next three months or scheduling phone calls with organizations, medical societies and other networks to identify prospects within the next six months.

A few tips to support a diverse, inclusive and equitable board:

- Be mindful to avoid tokenism when building a diverse board. This is not an effort to hit a quota, but rather an opportunity to invite meaningful change to bring diverse perspectives to the boardroom to better serve your community.
- If you have a medical advisory board, there may be a researcher, clinician or other expert in this network who already is involved in DEI issues in the community. Your medical advisory board may offer recommendations and ideas for finding medical experts who may be appropriate for your board.
- Integrate new board members by creating opportunities such as an informal social time to connect with them and learn about their interests.
- In the boardroom, all board members should be treated equally. This includes opening the conversation to each board member to pose questions, be heard and feel respected and valued. This creates an inclusive environment where everyone can do their best work.
- Consider what training might be needed to set your board up for success, such as a training on cultural competency. New board members with less experience could benefit from an overview of board responsibilities or trainings on specific topics like financial reviews and fundraising. Implementing a buddy system to pair new members with seasoned board members can support the learning process around board culture and real-life expectations.

BoardSource teamed up with Nonprofit Quarterly to create a webinar on “Practical Strategies for Board Diversity” to help you envision how you can start a change process with your board. To watch, visit: bit.ly/strategies-board-diversity

To meet your plan’s objectives and goals, set aside time quarterly or semi-annually to measure progress. Be open to feedback from new and existing board members as well as your community so you can modify strategies that are not effective. It may take time to notice the impact of your commitment to diversity and inclusion, but cultivating an environment supporting meaningful change will help your organization thrive and grow to meet the needs of those you serve.

Supporting Diverse Communities

Your organization will be better prepared to serve and support your community when led by an inclusive board focused on creating equity in the community. Your new board members can help identify the unmet needs of the population(s) you serve, particularly within underrepresented communities.

Outreach to diverse communities can be a daunting task since it can be difficult to know where to start. There is no one model that fits all, but here are some tips to get your organization started in creating a successful strategy.

Diversity Task Force

Forming a diversity task force can be helpful in informing your organization’s initiatives. This is an opportunity to ensure representation of diverse voices, experiences and people who can meaningfully guide organizational strategy for DEI. Consider including diverse external stakeholders with expertise in diversity, equity and inclusion and voices from marginalized populations within your community. You can also lean

on the relationships you have with medical professionals, who can advise on which communities may be underrepresented and underserved in your disease state. If the medical professionals in your network are not representative of your community, consider doing further outreach to find practitioners who are familiar with working with underrepresented populations. You may consider medical societies involved in your larger clinical disease space (e.g., ASGCT for gene therapy, ASCO for oncology, ASH for hematology, AES for epilepsy, ATS and ALA for pulmonary, etc.) and find diversity experts who treat the larger disease communities. Contact NORD's Membership Team at membership@rarediseases.org for more information or ask others you trust in our larger rare community.

DEI initiatives will be needed as long as health disparities exist. However, although you may be eager to tackle several initiatives at once, your task force should work to identify one or two specific needs to address first. This will keep your team focused and set your organization on a path to long-term success with concrete and achievable goals.

Landscape Analysis

Performing a landscape analysis is one way to help your organization better understand your community. You can utilize the data to inform your DEI strategies. Your task force can design a survey to send to your network to help identify the needs of your underserved populations. You can also take advantage of your virtual and in-person events to have individual conversations with your community members who may need specific support based on their gender, sexual orientation, age, race or ethnicity.

It is critical to solicit and hear the needs of your community so you can strategically design the right programs and services that align with their requests.

Programs and Services

Once your organization has identified the individuals in your community who need additional support and outreach, you can design new programs and services to help address their needs. Include their voices in the planning, design and marketing of your programming to help ensure optimal utilization of those programs by the entire community. Rely on your social media channels to help your organization promote new initiatives and connect with this audience further. Find ways to incorporate human interaction into your programs to foster a connected community, such as hosting video calls for specific support groups. You may find that some programs or services work better than others, so use those findings to revise your strategy moving forward.

While there are many ways you can outreach to and support diverse communities, it is important to consider your organization's capacity for successfully implementing initiatives and supporting these communities in ways that are culturally competent and meaningful.

Start small and start where you are, even if that's not knowing where to start. Identify one area that needs your attention and take small steps forward. Listen to your community and what is important to them. And don't be afraid to take some risks so you can learn from those experiences to improve your organization's outreach and impact each and every year.

REFERENCES:

Beyond Political Correctness: Building a Diverse and Inclusive Board (BoardSource)

bit.ly/beyond-political-correctness

Taking Action on Board Diversity: Five Questions to Get You Started (BoardSource)

bit.ly/taking-action-board-diversity

6 Tips to Help Your Nonprofit Improve its Outreach with Diverse Communities (Bloomerang)

bit.ly/improve-outreach-diverse-communities

DEI Case Studies from NORD's Rare Cancer Coalition (NORD Webinar)

bit.ly/NORD-DEI-case-studies

Where is Race on Your Board's Recruitment Agenda? (BoardSource)

bit.ly/race-board-agenda

Diversity, Inclusion, and Equity (BoardSource)

bit.ly/DEI-BoardSource

Diversity, Equity, and Inclusion (DEI) in the Nonprofit Sector – Essential Resources for Nonprofit Professionals (Bloomerang)

bloomerang.co/resources/dei

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