

DIVERSITY, EQUITY AND INCLUSION (DEI) TOOLKIT

for Rare Disease Patient Organizations

A resource from the
National Organization for Rare
Disorders (NORD®) for patient
advocacy groups

3



PART 3

BOARD DIVERSITY: GROWING
YOUR BOARD OF DIRECTORS
TO REFLECT YOUR DIVERSE
COMMUNITY

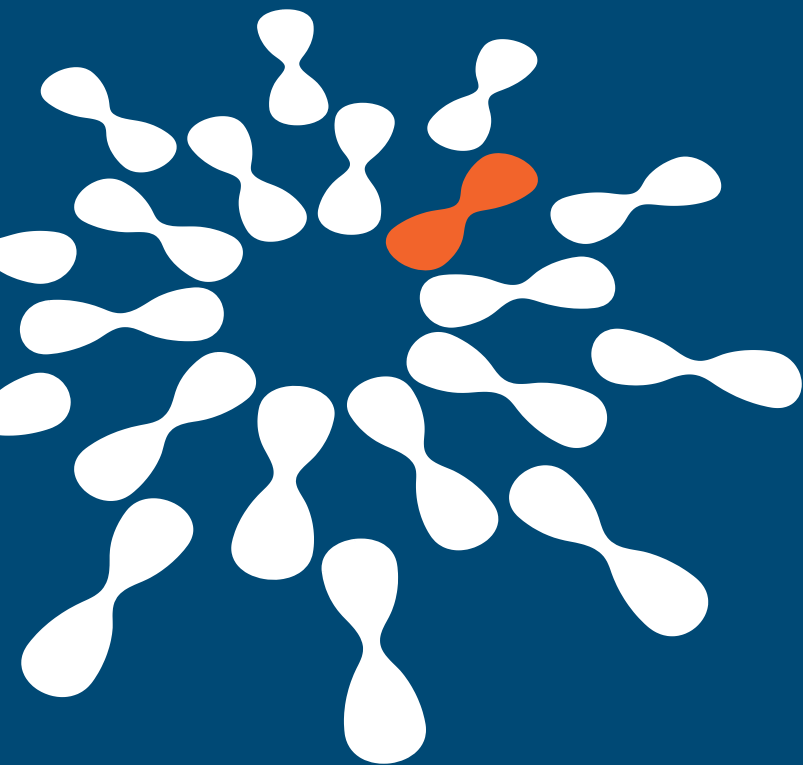


PART 3

BOARD DIVERSITY: GROWING YOUR BOARD OF DIRECTORS TO REFLECT YOUR DIVERSE COMMUNITY

CONTENTS

An Introduction to NORD	2
Overview	2
Objective	2
Board Diversity: Growing Your Board of Directors to Reflect Your Diverse Community	3
Before You Get Started: Assess Your Organizational Culture and Avoid Tokenism	4
Take Action: How to Diversify Your Board	5
Introductory Level: Basic Recruitment	6
Worksheet: Goal Creation	7
Intermediate Level: Inclusion	8
Advanced Level: Rethinking your Board Structure	8
Take Action: Recruiting for a More Diverse Nonprofit Workplace	10
Hiring	10
Onboarding	12
Retention	13
Additional Resources from NORD	14
Acknowledgements	14
Feedback	14
Glossary of Terms	15



AN INTRODUCTION TO NORD

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community, driving supportive policies, furthering education, advancing medical research, and providing patient and family services for those who need them most. Together with over 300 disease-specific member organizations, more than 17,000 Rare Action Network advocates across all 50 states, and national and global partners, NORD delivers on its mission to improve the lives of those impacted by rare diseases.

Ensuring that everyone with a rare disease can access high quality health care, diagnostics, treatment and support has always been at the foundation of NORD's work. As an umbrella organization, our mission includes representing and supporting our member organizations and all rare disease nonprofits to fulfill their missions of advancing research, finding cures, and supporting their communities. In continuation with our commitment to diversity, equity and inclusion (DEI) – and in response to our members' interest in this area – NORD has developed a foundational series of webinars and toolkits, to address how marginalized groups are impacted by rare diseases, and what we can all do as leaders in the space to improve the lives of people living with rare diseases.

Overview

A nonprofit board of directors sets the tone for the entire organization. Board diversity is essential to developing a more inclusive environment for staff, clients, partners, and community members. It is not uncommon to see a disconnect between boards and the communities they serve, which can lead to misinformed and ineffective decision-making.

Diverse representation in board leadership allows an organization to better understand the voices and perspectives of communities they serve, including their concerns, interests, and ways to create sustainable partnerships.

This third part in NORD's DEI webinar and toolkit series will help organizations create measurable strategies to assist their boards in implementing DEI training and provide tools to assess their own implicit bias. In addition, this toolkit will discuss ways to implement recruitment practices and processes that will enhance an organization's potential to better serve its community through sustainable best practices.

Objective

This final toolkit in the series is focused on assessing the diversity of nonprofit boards and creating strategies to further diversify board members and the workplace to enhance discussion, decision-making, and the overall impact of the organization in its community. This toolkit will:

- Define key terminology related to DEI best practices.
- Provide tools and checklists to help nonprofit leaders diversify their board and create an inclusive organizational culture.
- Offer best practices for building and retaining a more diverse nonprofit workplace.
- Share resources and further reading recommendations to explore these topics.

Board Diversity: Growing Your Board of Directors to Reflect Your Diverse Community

“When a nonprofit’s board reflects the diversity of their community, the organization will be better able to access resources in the community through connections, with collaborative partners, coalition building or potential donors. You are also able to better meet an unmet need that you may not otherwise be connected to or know about.”

YOLANDA AVENT, PHD, FOUNDER AND CEO, AVENT DIVERSITY CONSULTING

According to a survey by BoardSource,¹ 84 percent of nonprofit board members are white, and more than one quarter of all nonprofit boards are entirely white. What’s more, nonprofit board chairs and chief executives are dissatisfied with their current levels of board diversity but have low prioritization of taking action to increase demographic diversity in board recruitment. Identities are intersectional, meaning that people can have more than one marginalized identity, which can contribute to their limitations and access to resources. To provide the best support and advocacy for all people living with rare diseases, rare disease nonprofits must address the diversity of their patient groups, identify barriers and facilitate access to healthcare.

Why Diversify Your Board?

As the governing body of any nonprofit, a board should reflect the people that it serves, in order to infuse cultural competency and diverse perspectives into the organization and further its mission. With a homogenous board, implicit bias and unintentional exclusion may be hindering your inclusion and outreach efforts. With a diverse board, you will have access to more communities, engage in more nuanced dialogues, and propel your organization forward with progressive values.

List the benefits having a more diverse board holds for your organization. This will help advance your work.

BENEFITS OF HAVING A MORE DIVERSE BOARD

Benefit #1

Benefit #2

Benefit #3

Benefit #4



Get inspired! Waleska Lugo De Jesus, MPA, CEO of Inclusive Strategies, LLC and founding director of the Healing Racism Institute, shares her personal experiences with board diversity and inclusion in this TEDx talk bit.ly/board-diversity-video



Further Reading: Learn more about the “why” behind board diversity in healthcare, and some key questions to be asking your board with this article from the American Hospital Association, How and Why to Increase Board Diversity bit.ly/increase-board-diversity

Before You Get Started: Assess Your Organizational Culture and Avoid Tokenism

Nonprofit leaders understand and appreciate diversity but may fall into the trap of “checking off a box,” simply identifying a prospective board member based solely upon some quality of the individual’s identity and not the individual’s unique or underrepresented perspectives, skills or experiences. Tokenism is the practice of making only a symbolic effort to do a particular thing, especially by recruiting a small number of people from underrepresented groups to give the appearance of sexual or racial equality within a workforce. It is diversity without inclusion.

Here’s a definition of tokenism from Helen Kim Ho, [📄 8 Ways People of Color are Tokenized in Nonprofits](#):

There’s a type of racism in the workplace many of us have personally witnessed, perpetrated or experienced: tokenism... Tokenism is, simply, covert racism. Racism requires those in power to maintain their privilege by exercising social, economic and/or political muscle against people of color. Tokenism achieves the same while giving those in power the appearance of being non-racist and even champions of diversity because they recruit and use people of color as racialized props.

To avoid tokenism, make sure to keep in mind how each new board candidate fits into your overall goals as well as your diversity goals. Articulate this to each new board candidate in a personalized manner that is specific and candid.

For example, if your goals include both connecting with the Hispanic/Latino/Latinx community and someone with finance experience, you may want to look specifically for a Hispanic/Latino/Latinx individual in the financial field who has done volunteer work in the local Hispanic/Latino/Latinx community. When fostering a prospect, share with them the specific parts of their resume that align with your overall and diversity-specific board recruitment goals. Transparency and authentic relationship building are key to building trust. We have included sample board demographics survey questions below, but you can take a [📄 deeper dive here](#).

SAMPLE BOARD DEMOGRAPHICS SURVEY QUESTIONS	
Gender	<ul style="list-style-type: none"> • Woman • Man • Nonbinary/Genderqueer • Transgender/Trans* • Two spirit • Not Listed here: [open-ended]
Race/Ethnicity	<ul style="list-style-type: none"> • African-American/African/Black • Asian-American/Asian/Pacific Islander • Native American/Indigenous/First Nations/American Indian/Alaska Native • Middle Eastern/Arab/Arab-American/North African • Hispanic/Latino/Latinx • White/Euro-American • Mixed Race/Multiracial • Not listed here: [open-ended]
Military Status	<ul style="list-style-type: none"> • Are you an active military personnel or a veteran?
Disabilities	<ul style="list-style-type: none"> • Do you consider yourself to have a disability?
Identities	<ul style="list-style-type: none"> • Any other identities you would like to share?
What are your areas of expertise? [list desired areas]	<ul style="list-style-type: none"> • Financial • Board governance • Legal • Marketing and communications • Research and registries • Information technology • Development/Fundraising • Social media • Advocacy, policy • Diversity, equity, inclusion • Youth organizing • Not listed here: [open-ended]



Further Reading:

- Check out this short and amusing article on the state of nonprofit boards and how to increase diversity and inclusion: The Real Reasons Many Organizations are Still Unable to Diversity Their Board, Staff and Fundraising Committees, bit.ly/lacking-diversity
- Check out the Governance Institute’s “Building a More Diverse Board” toolkit, bit.ly/building-board-diversity

Take Action: How to Diversify Your Board

What can you do to improve representation and diversify your board of directors? What is your role in creating an inclusive and equitable board culture? Depending upon where your organization lands in the lifecycle of a nonprofit (e.g., startup, operational board, guidance board,) you may be better positioned to do more advanced board outreach. But what if your organization – like many rare disease nonprofits – is feeling the strain of limited human resources and financial resources? We detail three levels of activities and strategies involved for diversifying your board.

[Introductory Level: Basic Recruitment →](#)

[Intermediate Level: Inclusion →](#)

[Advanced Level: Rethinking your Board Structure →](#)



Introductory Level: Basic Recruitment

This is the first step to diversifying your board.

TASK	DETAILS	STAFF/LEADERS ASSIGNMENT
Conduct a Board Demographics Survey	Figure out the current makeup of your board by doing a board demographics survey. You can compare this to local demographics or those of the community you serve as a starting point.	
Create a Board Recruitment Committee	If they are willing, ask board members of color and board members from other marginalized communities to be on that committee. Make sure you acknowledge that it takes a lot of work to do recruit and give them the support and time that they need.	
Identify Prospects	Identify prospective board members and build a relationship with them. It can take time to make a person feel connected enough to your organization to become a board member.	

Worksheet: Goal Creation

Outlining your goals around board recruitment can help focus your efforts and assist you in articulating the value of new board members beyond their identities.

What are your overall goals when recruiting new board members in general?

Goal #1 _____

Goal #2 _____

What are your goals with diversifying your board? Think specifically when making this list, so your recruitment can be as focused as possible.

Goal #1 _____

Goal #2 _____

Keep in mind that this is a brainstorming list, not a contract.

GOAL	# OF CURRENT BOARD MEMBERS	# OF DESIRED BOARD MEMBERS	RECRUITMENT STRATEGY	PROSPECT & CONTACT INFO
EXAMPLE: Increase Hispanic/Latino/a/x representation on the Board by connecting with leaders in the community	1	3	Approach the Chair of the Hispanic Advisory Committee of the local hospital for discussion and ideas.	TBD

Intermediate Level: Inclusion

Creating an inclusive board and organizational culture is integral to retention of board members from underrepresented communities.

- Should you eliminate financial donation as a board requirement? Read one argument on why we need to drop the idea of a giving board bit.ly/board-giving
- Make your board more engaged:
 - If you do not already have board committees, think about establishing them. Each committee can hone the strengths of the board members in them and work on action items that support the staff.
 - Make sure your committee structure is practical for both your organization and the board members. They should feel like they are actively contributing, and you should feel like they are making a practical difference.
 - Add a social component to board meetings or arrange events to promote board socialization. This can make the board excited to go to meetings, and to be on your board. You can even establish a “board engagement” committee that plans and organizes these social components.



Further Reading: This one-pager bit.ly/inclusion-handout from Tangible Development, a DEI consulting firm, lays out immediate to long-term steps toward inclusion on your board.



Reflection for Nonprofit Leader

- *What practices will you implement at your organization to promote an inclusive environment on your board?*
- *How will you welcome new board members and create an environment of inclusion?*
- *What steps will you take to prevent tokenism?*

Advanced Level: Rethinking your Board Structure

The conventional nonprofit board structure can be difficult to work within and can be problematic. It might be that the current operation of your board needs to be fully revamped in order to make big strides in DEI and make the board work for your new way of operating. Many nonprofits are thinking of innovative ways to restructure their boards. It would certainly be a big change, but if you are at this stage, your organization might be ready for it.

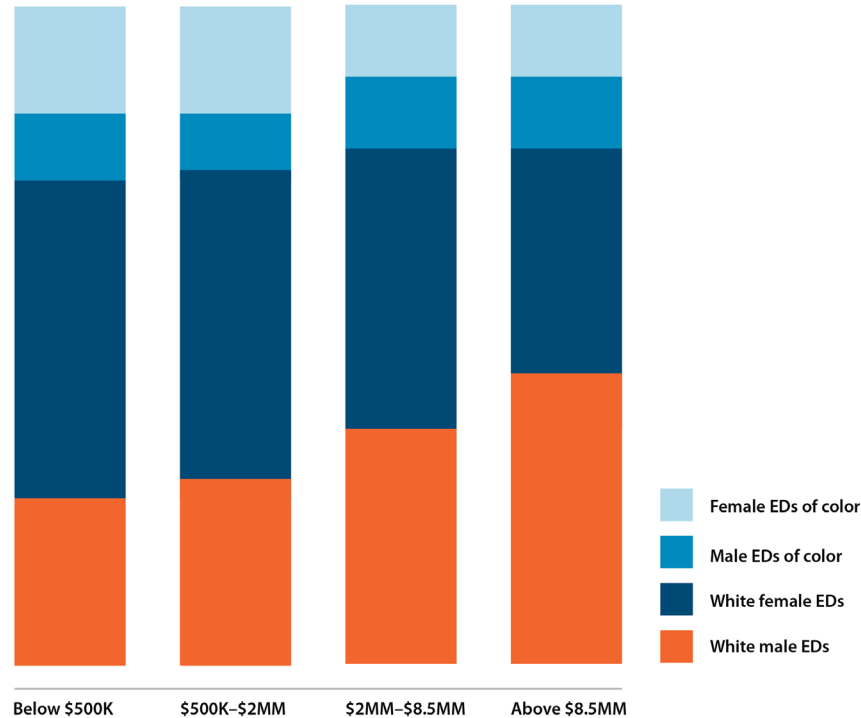
- What is your current board structure?
- What are the strengths of your board?
- What are the weaknesses of your board?
- In an ideal world, what would your board look like and how would it function?
 - What elements of this ideal board are “low hanging fruit” (or easily attainable) that you can implement now?
 - What elements of this ideal board do you want to try to implement in your current board structure?
- If you are considering a board redesign, what would all of the steps be? Write them out, with as long of a timeline as is needed. Major change takes time!
 - Get board buy-in: start conversations with the board on your long-term plans. They can help make it happen! Know that some people will resist change, but you need to do what is best for the organization and your constituents.



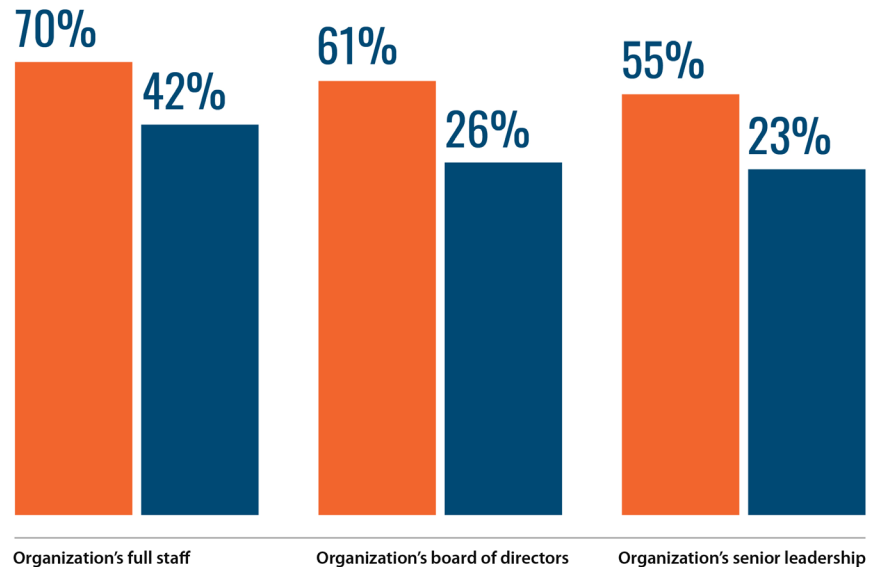
Further Reading:

- “The Default Nonprofit Board Model is Archaic and Toxic, Let’s Try Some New Models” bit.ly/old-board-model
- Check out this Board Diversity, Inclusion and Cultural Competency resource library for more reading, watching, and toolkits bit.ly/DEI-cultural-competency
- Nonprofit leadership demographics bit.ly/leadership-diversity

Demographics of Executive Directors by Budget Quartile



- Nonprofit CEOs who believe that in order for their organization to achieve its goals, it is **very or extremely** important for each of the following groups of people to reflect the population(s) the organization seeks to serve
- Nonprofit CEOs who believe that each of the following groups of people reflects the population(s) the organization seeks to serve **very or extremely** well



Take Action: Recruiting for a More Diverse Nonprofit Workplace

While this toolkit focuses on board diversity, here we touch on diversity in the rest of the organization. See below for some best practices in recruitment, hiring, and retention. If you're serious about DEI and accessibility, you'll need to put an effort into getting the word out about your organization to marginalized communities. See the toolkit for Webinar #2 ("Membership Inclusivity") for where to start on community engagement at your organization.

Additional strategies you can put into action are:

- Have a percentage benchmark of candidates of color, such that you do not close a job posting until that percentage is reached. You must collect this data anonymously so that it does not affect hiring. We found Washington State University's [📄 Frequently Asked Questions for Collection of Personal Demographic Information](#) and the [📄 Career Place](#) to provide particularly useful tips for consideration.
- Internships require unique recruitment, so do not rely entirely on the way that you market and recruit your staff positions. Depending on the age demographic you are looking for, advertise through schools, especially researching schools in your area with diverse demographics like community colleges or HBCUs (Historically Black Colleges and Universities). You may want to contract a recruiter who specializes in internship recruitment. Once you have built those relationships, recruitment in future years will be much easier.
- When possible, consider opening up your employment opportunities to fully-remote options as it can break down geographic areas if your office is located in a homogenous area in the country.
- Make sure your whole staff knows about job postings so they can share them with their networks.
- Social media will be lucrative for recruitment, consider using Instagram, Facebook, LinkedIn and yes, even Tiktok!²

Hiring

- Put together a diverse hiring panel for every new hire. When doing this, make sure that non-white employees are not over-used on hiring panels, and that they are able to opt-out if they do not have capacity. Articulate why you would like their expertise when inviting them on a hiring panel beyond their race to avoid tokenism. If you do not have enough non-white or non-male employees, consider contractors or volunteers to be on hiring panels as well.
- Follow the "Rooney Rule," (see [glossary](#)) where at least one qualified person of color must be interviewed before hiring, while being mindful of tokenism.
- Include a DEI and accessibility question in your interviews to assure that all new employees are aligned with this work. This will help propel your work forward and shift organizational culture. Sample questions:
 - What learning have you done around inclusion, diversity, equity, and accessibility?
 - How do you see diversity, equity, and inclusion principles applying to this role?
 - How do you define inclusion, diversity, equity, and accessibility?
 - How does it affect your life and work?
- Implicit Bias: be aware of biases that may disqualify talented candidates before they even have the chance to sit down for an interview. You can do this by utilizing **Values-Based Interviewing**.
 - Values-Based Interviewing means identifying the core competencies (the "what") of the role and also the values (the "how") of your organization. Often a candidate will not have direct experience in the role you are seeking to fill, but their experience may be extremely applicable to your organization. The core competencies, the daily routines of the role, can often be taught during training (especially for entry level/volunteer/lower level staff positions) but if the individual does not evoke the values of your organization it will be more difficult to seamlessly integrate them onto your team.

- **EXAMPLE:** Your organization is seeking a volunteer training lead, this is a full time position that is responsible for the training and continued development of volunteers. You have an applicant who doesn't have experience specifically working for a nonprofit, but they have seven years of retail leadership experience. You identify during an interview with value-based questions that this individual possesses the values that your organization stands by and though their experience is not direct, it is applicable.
- Values-Based interviewing is important because discrimination of all types keeps talented individuals from getting the experience needed to progress in their careers. Knowing what your organization stands for and hiring individuals who align with those values and giving them the on-the-job training necessary to set them up for success can not only benefit your organization by adding to a diverse culture but will be benefitting society as a whole.
- Determine whether Values-Based Interviewing is right for your organization using this resource <https://bit.ly/value-hiring>
- Sample Interview Questions:
 - Tell me about a time that you had to give feedback to a leader on a mistake that they made. How did you approach it and what was the outcome of the conversation? Value: Direct communication.
 - Tell me about a time when you faced a situation that required you to act with trust and integrity - what was the outcome of the situation? Have you ever been involved in a situation where your personal values came in conflict with your professional values? How did you handle it? What was the outcome? Values: Trust, ethics, and integrity.
- Consider that you may be operating with unconscious bias and may make assumptions about someone's experience. For example, a person with years of experience in a different industry will have horizontal skills

that can transfer to your work – and may bring more to the position than you assume. It's important to ask open ended questions about the attributes needed to be successful in the role NOT just looking for similar experience. Focusing on examples of teamwork, leadership, feedback, training, development are all great places to start. (Now, there are some roles that will obviously require more relevant experience than others, if you are hiring a grant writer, you need to hire someone who is qualified to do that work.)



Further Reading:

- Better understand the considerations around hiring people with disabilities, and the benefits in this article bit.ly/disability-hiring and this video bit.ly/employment-disabilities
- Here are some more steps toward diverse hiring bit.ly/diversity-hiring-steps

Onboarding

How do you welcome and prepare new staff members on their first day, first weeks and first months on the job? Are you prepared for their onboarding? Do you have a welcome packet ready? Are you setting time aside for the onboarding or is it being put together at the last minute because of a lack of human resources? Are you allocating time for questions or is the orientation being rushed?

First impressions set the tone and a good onboarding experience will make or break a relationship, especially with volunteers/ junior-level employees. Make sure you have consistency in your messaging around DEI for staff, volunteers and interns. Taking frequent inventories on your organization's work towards DEI will be helpful in staying accountable to your goals.



EXAMPLE ONBOARDING SHEET	CHECK OR SIGN OFF WHEN COMPLETED
Preparing for Onboarding	
Name tag printed	
Hiring paperwork printed/organized in folder	
Employee first schedule completed	
Training plan written	
Onboarding	
Is the meeting space clean/organized?	
Welcoming environment?	
Prepared (pre-OB complete)?	
Safety walk/tour complete	
Role overview	
Handbook overview	
Policy and Procedure check in/sign off	
Training plan presented	
Post-Onboarding	
Training plan follow up	
Paperwork submitted/filed	
30/60/90 day plan written and delivered	

Retention

Retention begins during the recruitment process. Having consistent routines in place for recruits is crucial to ensure that all applicants are having the same positive experience. For smaller organizations, recruitment is also about building your brand and culture. There will be many candidates you interview but do not hire, and you don't want them to walk away from your organization with a bad impression of your organization and culture.

As you increase diversity in your organization, you will need to create new intentional strategies for retention. DEI takes work, and it will be an ongoing process to create an inclusive environment for all. Marginalized identities face constant stresses due to microaggressions, implicit bias, and systemic disparities. Therefore, retention strategies are also inclusion strategies.

Here are some additional best practices:

- Define paths to leadership that are open and transparent.
- Encourage the building of trust and relationships to help employees feel comfortable sharing their experiences. For example, create affinity groups to help foster mentoring opportunities and safe spaces.
- Involve underrepresented communities and people of color in the discussion and decision-making process.
- Establish mentors for new employees.
- Make sure employees from underrepresented communities have access to leadership for mentorship, communication, and networking.
- Hold bias training for executive leaders, management, hiring committee, and general staff, and continue routine training and dialogue.
- Encourage and incorporate individual professional development opportunities that promote self-awareness, personal growth, and a safe working environment.

- Remove policies that cause people of color to feel as though they cannot be their true selves, which includes restrictions on appearance, affiliation, and association. For more support on how to do this, check out this article, Watch Out: Five Types of Bias in Human Resources bit.ly/bias-human-resources



Reflection for Nonprofit Leader

How did you feel as a new employee going through hiring and onboarding at your organization? Which of these practices could have improved your experience as a new employee?



Further Reading:

Go deeper into human resources best practices through BoardSource, which provides a Personnel E-Policies Sampler booklet bit.ly/epolicy-sampler at a reduced rate for NORD Member Organizations. If you have an HR professional on your Board or staff, they may already be a paid, professional member of the Society for Human Resource Management (SHRM) which offers a resource hub of HR best practices at <https://www.shrm.org/>. You may find SHRM to be worth the annual dues if your organization requires a substantive HR review, evaluation and/or overhaul.

Additional Resources from NORD

1. NORD DEI Webinar and Toolkit Series

Navigating DEI in Rare Disease Nonprofits

Landing Page: bit.ly/nord-dei

Toolkit #1: bit.ly/nord-dei-toolkit1

Toolkit #2: bit.ly/nord-dei-toolkit2

Membership Inclusivity: Who's Left Out?

Webinar: bit.ly/Membership-Inclusivity

Board Diversity: Growing Your Board of Directors to Reflect Your Diverse Community

Webinar: bit.ly/BOD-Diversity

2. Nothing About Us Without Us: The Communities' Role in Recruitment and Engagement

NORD RareLaunch program (login required, free to access):

<https://bit.ly/nord-research-ready>

3. "Representation Matters"

NORD RareLaunch Toolkit: bit.ly/nord-representation-matters

Acknowledgements

We are grateful to those who have helped us by providing expertise and feedback on this toolkit during its development. The toolkit was informed by Avent Diversity Consulting LLC, led by their President and CEO, Yolanda Avent, Ph.D. Dr. Avent has been working in the field of Diversity, Equity and Inclusion for more than 20 years. We would like to recognize all of the speakers who participated in NORD's DEI Webinar series:

Yolanda Avent, PhD, Avent Diversity Consulting

Ashanthi De Silva, MPA, Membership Manager, NORD

Walter L. Douglas, Jr., Rutgers, New Jersey Medical School

Debbie Drell, Director of Membership, NORD

Ashley Ferreira, MPA Immune Deficiency Foundation

Janette Merrill, MS Ed, American Society of Clinical Oncology

Keri Norris, PhD, MPH, MCHES, National Hemophilia Foundation

Vinicio de Jesus Perez, MD, Stanford University Medical Center

Feedback

NORD's Membership Team welcomes your feedback and questions about this toolkit. Please reach out to us at membership@rarediseases.org.

GLOSSARY OF TERMS

Accessibility

The design of products, devices, services, or environments so as to be usable by people with disabilities. One definition of accessibility is “an umbrella term for all aspects which influence a person’s ability to function within an environment.”³ Accessibility is a measure of how simply a person can participate in an activity.

At-Risk

This term highlights the systemic oppressions that create disproportionate barriers for certain people. Usually this term is used for youth to point out the higher likelihood that some youth could underperform in school or misbehave due to socioeconomic factors. This term is avoided by some because of the negativity that it implies in predicting youths’ futures.

Attractionality

This term describes to whom a person is sexually attracted. Some people are attracted to people of a particular gender; others are attracted to people of more than one gender. Some are not attracted to anyone.

Bias

Prejudice in favor of or against one thing, person, or group compared with another, usually in a way considered to be unfair.

BIPOC

Black, Indigenous, and People of Color – this term references any person who does not identify as white (including mixed-race people). This term highlights the unique positionality of Black and Indigenous communities as disproportionately affected by systemic oppression as compared to other people of color.

Cultural Competence

Cultural competence is a set of behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or those professions to work effectively in cross-cultural situations. The word culture is used because it implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious or social group. The word competence is used because it implies having the capacity to function effectively.

Engagement vs. Outreach

Outreach refers to one group “reaching out” to or informing another group. This implies a more transactional, or one-way directional relationship. Engagement implies a mutual relationship between the two groups, and a two-way dialogue involving listening and sharing.

Equity

The fair treatment, equality of opportunity, and equality of access to information and resources for all. This becomes possible when we build an environment rooted in respect and dignity and take action to ensure equitable access for all communities in the rare disease space.

Gender Expression

The way in which a person chooses to communicate about gender to others through external means (e.g. appearance, mannerisms and/or clothing). This communication may be conscious or subconscious and may or may not reflect a person’s gender identity or sexual orientation.

Gender Identity

A person’s deeply held core sense of self in relation to gender. Gender identity does not always correspond to biological sex.

Inclusion

The 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.

I.D.E.A.

A term that builds on DEI to include accessibility: Inclusion, Diversity, Equity, and Accessibility.

Intersectional

The complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, and classism) combine, overlap, or intersect especially in the experiences of marginalized individuals or groups.

Marginalized

Marginalized groups refer to communities excluded from mainstream social, economic, educational or cultural life, often excluded due to race, gender, identity, physical ability, sexual orientation, language barriers, age, or other status.

Micro-Affirmation

Micro-affirmations replace messages about deficit and exclusion with messages of excellence, openness, and opportunity (e.g. giving praise to someone).

Microaggression

Brief and commonplace daily verbal, behavioral, and environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative racial, gender, sexual-orientation, and/or religious slights and insults to the target person or group.

POC

People of Color – a term that refers to any person who does not identify as white (this includes mixed-race people).

Privilege

When one group has something of value that is denied to others simply because of the groups they belong to, rather than anything they've done or failed to do.

Rooney Rule

Adopted in 2003, the Rooney Rule is an NFL policy requiring every team with a head coaching vacancy to interview at least one or more diverse candidates. The Rooney Rule is named after the late former Pittsburgh Steelers owner and chairman of the league's diversity committee, Dan Rooney.

Serve

This term implies a power dynamic, in which one group is serving the other. However, this may be appropriate for use in certain instances, such as in the medical field when talking about patient care.

Social Identity

An individual's knowledge of belonging to certain social groups, together with some emotional and value placed on being a member of that group.

Systemic Disparities

Systemic racism creates disparities in many "success indicators" including wealth, the criminal justice system, employment, housing, health care, politics, and education. These disparities disproportionately impact people of color.

Tokenism

The practice of making only a symbolic effort to do a particular thing, especially by recruiting a small number of people from underrepresented groups in order to give the appearance of sexual or racial equality within a workforce. It is diversity without inclusion.

Unconscious/Implicit Bias

Social stereotypes about certain groups of people that individuals form outside their own conscious awareness.

Under-invited, Under-heard

These terms put the responsibility on those in power to hear or invite communities, instead of blaming communities themselves for being marginalized.

Underprivileged

A group that does not benefit from systemic power and privilege. This term is often avoided because it implies that a community does not have any privilege, when they may feel their community or identity offers them many privileges (outside of systemic power).

Underrepresented

This term outlines when a group's representation is not proportionate to their population.

Underserved

This term highlights the systems that put people in the margins and do not serve them. It makes the problematic assumption about who is responsible for determining and directing services, as well as who is at the receiving end of services.

Unintentional Exclusion

This happens when there are exclusive opportunities that oftentimes require participants to have access to certain tools, resources, or knowledge. The unforeseen barriers may not be intentional but still can exclude others from participating.

ENDNOTES

1. <https://blog.boardsource.org/blog/reflections-on-trust-and-its-relationship-to-racial-inequity-on-nonprofit-boards>
2. <https://www.shrm.org/hr-today/trends-and-forecasting/research-and-surveys/pages/social-media-recruiting-screening-2015.aspx>
3. <http://www.accessibleuniversity.com/accessibility-basics/defining-accessibilityhttps://documentcloud.adobe.com/link/track?uri=urn:aaid:scds:US:2d892c0a-8c0e-4eb9-8bb1-c12402526922>

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 300 patient organization members, is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient services.



Massachusetts Headquarters: 1900 Crown Colony Drive, Suite 310, Quincy, MA 02169 | 617.249.7300
Connecticut office: 55 Kenosia Avenue, Danbury, CT 06810 | 203.744.0100
Washington, DC office: 1779 Massachusetts Ave. NW, Suite 500, Washington, DC 20036 | 202.588.5700

RAREDISEASES.ORG

©2022 NORD, its icon and RareLaunch are registered trademarks of The National Organization for Rare Disorders, Inc. All rights reserved.

NORD: Fighting for the rare community every day for nearly 40 years. NORD is committed to the identification, treatment and cure of rare disorders through programs of education, advocacy, research and patient support services. NORD does not recommend or endorse any particular medical treatment but encourages patients to seek the advice of their clinicians. NORD is a registered 501(c)(3) charity organization. NRD-2193