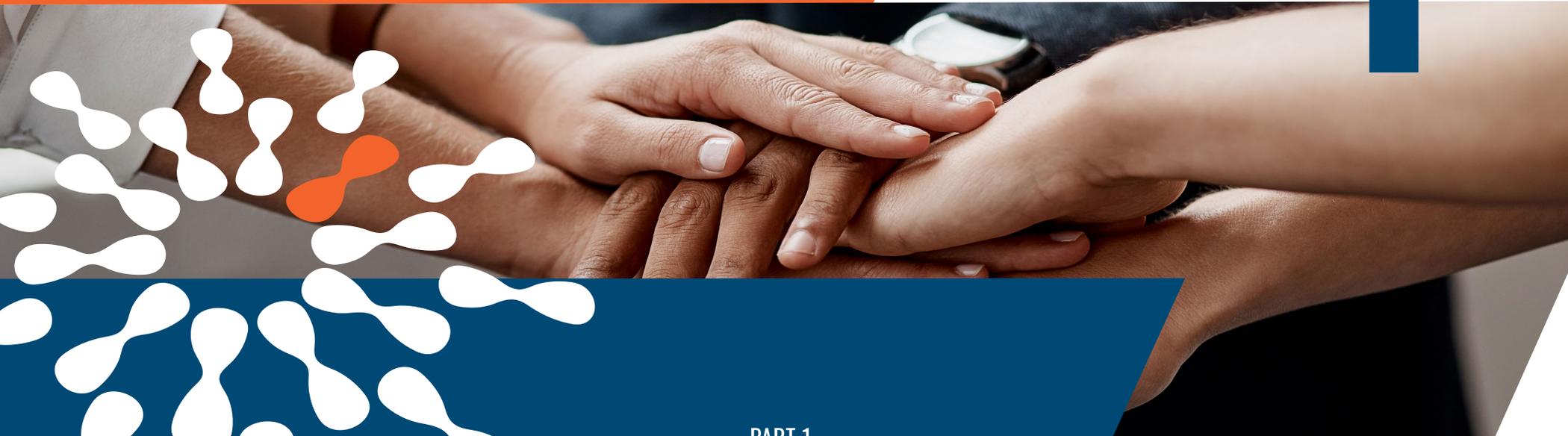


DIVERSITY, EQUITY AND INCLUSION (DEI) TOOLKIT

for Rare Disease Patient Organizations

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

1



PART 1
NAVIGATING DEI
IN RARE DISEASE
NONPROFITS

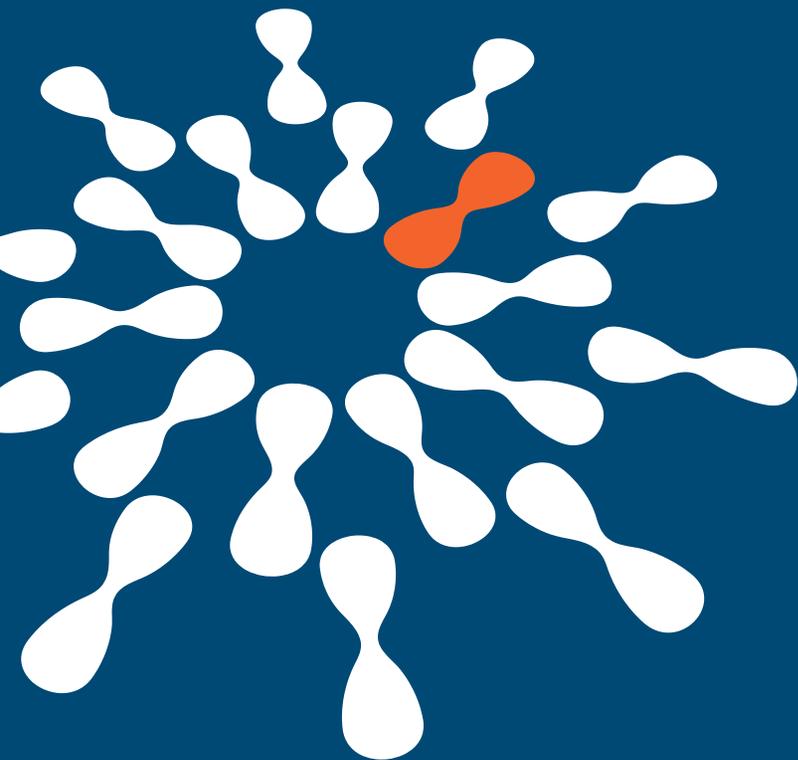


PART 1

NAVIGATING DEI IN RARE DISEASE NONPROFITS

CONTENTS

An Introduction to NORD	2
Overview	2
Objective	2
Why DEI Matters in Your Rare Disease Community	3
Take Action: How to Get Started with DEI	3
Social Determinants of Health	4
Stories from the Community	5
Gather Demographic Information Responsibly	5
Conduct an Accessibility Audit	5
Learn the Lingo	5
Understand Microaggressions and Practice Micro-Affirmations	5
Talk about Pronouns in the Workplace	6
Evaluate Your Company's Marketing and Visual Identity	6
Make an Ongoing Commitment	6
Consider Formalizing a Public DEI Plan of Action	7
Additional Resources from NORD	8
Acknowledgements	8
Feedback	8
Glossary of Terms	9



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 15,000 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 rare communities. In continuation with our commitment to diversity, equity, 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

Rare diseases do not discriminate – their impact can be felt by people of all genders, ages, races, ethnicities, socioeconomic statuses, religions, and sexual orientations. Leaders of rare disease nonprofits work hard to find and engage with as many patients as they can, but still may not be able to reach certain marginalized populations. How can incorporating DEI and accessibility initiatives help rare disease patient organizations connect with individuals seeking care, support, information and ways to get involved?

To be successful rare disease patient advocates – especially in a nonprofit organization – we must represent all rare disease patients. This requires an ongoing dedication to how we run our organizations and engage with our communities. With the help of DEI subject matter experts, NORD developed webinars and toolkits for leaders of patient advocacy groups who want to explore how focusing on DEI and accessibility efforts can help them be more effective and efficient in helping the rare disease community.

Objective

This toolkit aims to inform and guide patient advocacy groups as they seek to learn about DEI and accessibility principles and assess their work in these areas. The toolkit will:

- Define key terminology related to DEI best practices.
- Examine the unique position of rare disease patient advocacy groups and why DEI matters.
- Provide tools to help nonprofit leaders reflect on DEI work and take action.
- Share resources that further explore these topics.
- Set a foundation of knowledge that will build throughout the series.

Why DEI Matters in Your Rare Disease Community

In 2020 and 2021, a wave of social justice awareness and activism focused on the need to have strategies in place to support and implement diversity, equity and inclusion (DEI) initiatives. Companies and individuals engaged in work to better support those face ongoing marginalization, yet more remains to be done.

Due to low prevalence numbers, individuals and families who are impacted by rare diseases are part of a marginalized group, meaning they are sidelined from a healthcare system that is not yet optimized for their position, leaving them at a medical disadvantage.

There are urgent needs for treatment, research, and improved diagnostics, as 90–95% of rare diseases still lack an FDA-approved treatment and the average diagnostic journey lasts seven years with multiple misdiagnoses during that time. The rare disease community includes groups who are often further marginalized in society, health care, and research, such as BI-POC (Black, Indigenous, and People of Color) and the LGBTQIA+ (lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, including other sexual identities) community.

There are many groups who have been excluded and oppressed through systems and practices historically that still persist and exist today. Dismantling these barriers requires a collective effort working to liberate those who face ongoing marginalization. There is no one person who can fix all the social ills that exist. However, we can take a powerful step in this journey by using our voice, power, and influence to transform our organizations and communities.

In the workplace, committing to DEI strategies and best practices can offer many benefits, including an environment that better represents

the communities you serve. Those DEI practices can help foster working conditions in which employees take care of one another. This can result in improved business operations, such as recruiting and retaining talent by fostering a sense of belonging; incorporating a diversity of viewpoints and idea-sharing, creativity and innovation; and improving communication across the organization. From a business perspective, 91% of donors think a nonprofit's commitment to DEI is important.¹ With DEI practices in place, benefits ladder up so that patient advocacy groups are better able to support their patient communities.

“If you are leading a rare disease nonprofit, your community stories will vary, but we are united together in our goals for the future. We are working to provide a future with early diagnosis, support, education, treatment and cures for every single person with a rare disease.”

DEBBIE DRELL, DIRECTOR OF MEMBERSHIP, NORD

Take Action: How to Get Started with DEI

DEI work can take on a variety of forms. There are many ways to incorporate DEI principles and organizational changes in support of those principles and they don't have to be large or costly changes to your organization's day-to-day activities. Organizations can start small and build upon the changes over time.

Be an active listener: The first step to implementing DEI efforts is to listen and gather insights. It is important to understand how well your organization is serving diverse communities. Diversity encompasses identity, which is an individual's knowledge of belonging to certain social groups, such as gender, sex, race, ethnicity, education level, sexual orientation/attractiveness, religion, social class, age, disability, nation of origin and/or citizenship, tribal or indigenous affiliation, and body size.

To gain deeper insights when learning about others' experiences and discussing DEI, it can be empowering to reflect on terms like privilege, bias, and identity. Privilege refers to one group who has something of value that is denied to others – simply because they belong to a certain group(s), rather

than anything they've done or failed to do. Privilege can be used to oppress and deny others access to opportunities and rights.

Bias and identity are connected. When present in the field of healthcare, bias can result in the mismanagement of care for marginalized groups. Bias can appear in many forms, including stereotypes and unconscious lack of awareness; in many settings, such as patient-provider interactions and research participation; and on individual and institutional levels. For example, studies show people tend to look more favorably on those who share some aspect of their identity, and less favorably to those who are "other."²

Learn more: Watch this video of a sketch artist depicting, "Power Privilege and Oppression" (Graduate School of Social Work, University of Denver):

bit.ly/Power-Privilege



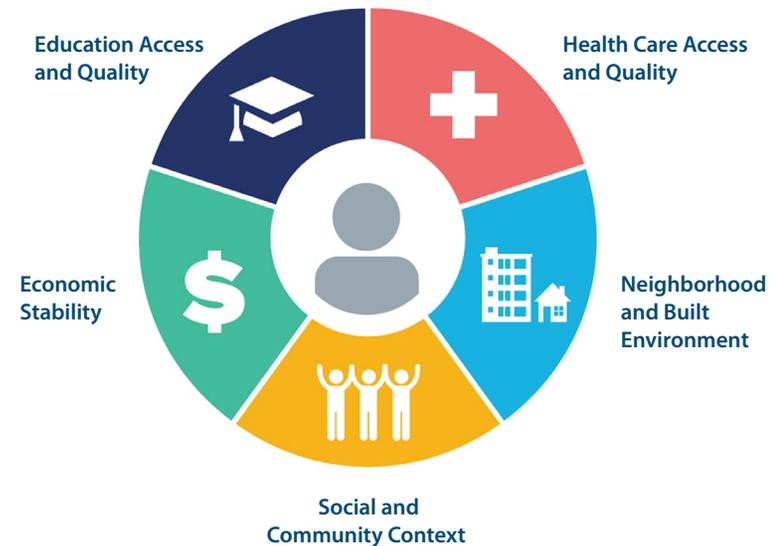
Reflection for Nonprofit Leader

- *What groups or communities do you identify with the most? The least?*
- *What privileges do you have based on your identity groups? How does privilege or lack thereof affect a person dealing with a rare disease?*
- *Was there a time where you or someone you love felt left out in the healthcare system because of your/their rare disease, identity, or both?*
- *Do you remember a particularly impactful or powerful patient story about how they were left out of the healthcare system because of their rare disease, their identity or even both?*
- *In your rare disease community, what groups are impacted by the disease? What groups are represented in your leadership, staff, volunteers, and advocates?*



Explore: Watch this video on implicit bias
bit.ly/Implicit-Bias-Concepts

Social Determinants of Health



Public health researchers have shown that environments and socioeconomic factors also have a significant impact on health outcomes. These factors may affect individuals' ability to seek and secure the resources needed for problems that arise due to health. For example, research indicates that your zip code can greatly influence your health – even more so than your genetic code. Examples of these social determinants of health include:³

- Safe housing, transportation, and neighborhoods
- Facing racism, discrimination, and violence
- Education, job opportunities, and income
- Access to nutritious foods and opportunities for physical activity
- Language and literacy skills

Stories from the Community: As a nonprofit leader, you must continuously look to learn from patients and caregivers about the factors that have had an impact on their rare disease journey. Create opportunities for them to share their experiences, collaborate, and help inform rare disease stakeholders' policies, programs, and research. These rare disease blogs highlight how social determinants of health and one's identities can directly influence the quality of care received:

- Beauty With a Twist: Black Disability and Racism, bit.ly/Beauty-Twist
- The Toll of Traveling Hundreds of Miles for Treatment Because I'm Rare, bit.ly/Traveling-Treatment
- Fibrous Dysplasia/McCune Albright Syndrome: Racial Healthcare Disparities, bit.ly/Racial-Healthcare-Disparities

Encourage your board, staff, and volunteers to keep learning as well!



Further Reading: See how your own zip code may impact your health bit.ly/Life-Expectancy-Location

Gather Demographic Information Responsibly: Collecting data can be an important tool to help you assess how well your community represents both the general population data by census and the population affected by your disease. Opportunities to solicit this information include event registrations, webinars, email newsletter signup forms, community polls, and research. Before you gather data, here are some sample questions and suggestions to consider:⁴

1. What is the purpose of the data collection tool being used (e.g. application, program evaluation), and do I need to collect demographic data?
2. Does the program or strategy want to reach a specific population? Why?
3. What are the criteria for distinguishing between “nice to know” and “need to know” data?

4. Do the data include personally identifying information?
5. Are there any data regulations to consider, such as HIPAA, FERPA or GDPR?
6. What are the plans to securely store the data?
7. Did you include explicit information about consent and confidentiality?
8. Are there options to select multiple check boxes, as well as include open text boxes?

Source: bit.ly/More-Than-Numbers

Conduct an Accessibility Audit: Accessibility refers to the design of products, devices, services, and/or environments so as to be usable by people with disabilities. Technology, such as access to wi-fi or websites accessible for the visually impaired, can create significant barriers for patients. Title III of the Americans with Disabilities Act (ADA) requires that most 501(c)(3) nonprofit organizations provide equal access to services, which includes digital content and functionalities. Nonprofits who receive federal financial funding (such as grants or loans) are also subject to sections 504 and/or 508 of the Rehabilitation Act,⁵ which closely aligns with the ADA. In order to meet these legal requirements, nonprofits need to ensure that their websites and digital assets meet the Web Content Accessibility Guidelines (WCAG) 2.0 (soon to be updated to 2.1) AA standards.



Further Reading: Beyond legal requirements, the ADA can help patient advocacy groups welcome individuals with disabilities into their organizations bit.ly/Affecting-Nonprofits

Learn the Lingo: It is important to use appropriate terminology when taking steps to build a diverse and inclusive environment, to help foster togetherness and avoid misunderstandings. Review and consult the [Glossary of Terms included at the end of this toolkit](#).

Understand Microaggressions and Practice Micro-Affirmations:

Microaggressions are slights, indignities, and put downs that members of

marginalized groups experience in everyday interactions. These stem from biases, and they work against inclusivity and other DEI efforts. Practice micro-affirmations to help create a positive, productive environment. Examples:

- Practice active listening, which focuses on hearing what is being shared clearly and demonstrating listening through eye contact, open body posture, summarizing statements, and/or asking qualifying questions to ensure understanding.
- Recognize and validate experiences, which involves elucidating the 'what, why, and how'. It is helpful to delve deeper by identifying and validating the constructive behaviors a person has demonstrated in order to respond to the experience both through expressing care about the effect of an event and demonstrating a willingness to think through a productive path forward.
- Affirm emotional reactions through verbal acknowledgement to recognize people have experienced something exciting, frustrating, or hurtful. This enables the conversation to focus on turning those feelings toward actions that will empower, heal, and/or foster learning.



Reflection for Nonprofit Leader

- *Take a moment to reflect on the definition of microaggression. Can you recall a time that you have been the victim of a microaggression? Can you recall a time where you may have micro-aggressed someone else?*
- *How do you think this relates to the level of care received and quality of life for those in the rare disease community?*

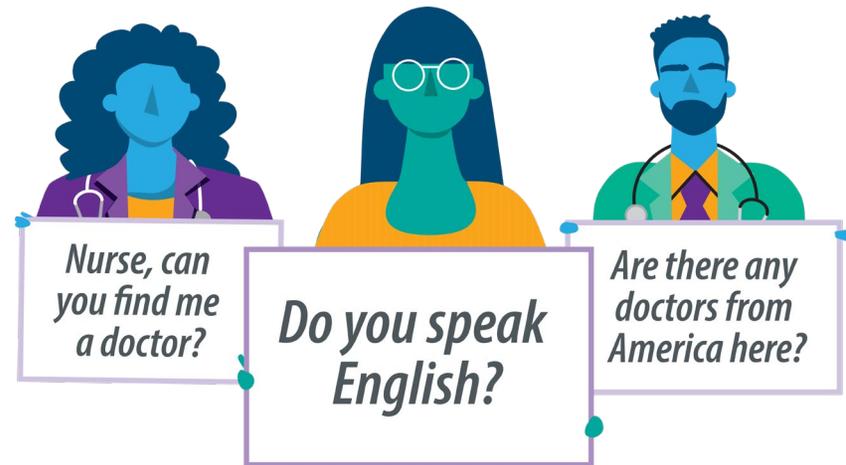
Talk about Pronouns in the Workplace: Do not assume pronouns based on gender expression. Show inclusivity by creating opportunities to validate an individual's personal gender identity and expression. Introduce pronoun sharing by role modeling it in a staff meeting. Consider implementing HR processes, such as adding pronouns to your email signature or an optional space to share pronouns during the onboarding process.



Further Reading: Accidentally misgendering someone can be embarrassing for both parties and may create tension and distraction in the workplace bit.ly/Pronouns-Workplace

Evaluate Your Company's Marketing and Visual Identity: Your company's visual identity should reflect your commitment to inclusivity. Examples:

- Take five minutes or more to explore and assess the diversity in your office pictures, website, magazines, resources, etc. Who is missing?
- Evaluate the quote in your signature on email. How can it be perceived by others? Can you use it as an opportunity to identify yourself as an ally or communicate the values of your organization?



Make an Ongoing Commitment: Doing this work can feel like a tall order. However, think of it as a marathon and not a sprint. There are small steps you can implement right now that can help your organization continually integrate and learn from DEI best practices.

Examples:

- Articulate an organizational commitment to inclusive excellence.
- Attend at least one DEI webinar quarterly and discuss learnings. Start with NORD's DEI webinar series, see [Additional Resources on page 8](#) to access the links to these webinar recordings.
- Introduce a new DEI-related term every week in a newsletter, website or other space.
- Create space for colleagues to recognize each other during staff meetings.
- Have people write "Where I am From"⁶ poems to establish common ground (for example: bit.ly/Where-I-Am-From).
- Monitor progress of DEI efforts to ensure they remain integrated and intentional.
- Assess your organization by analyzing its current practices, policies, and data using the [Inclusive and Equitable Organizational Development Continuum](#).
- Share your progress with staff, your Board of Directors and external audiences.

Consider Formalizing a Public DEI Plan of Action: With a formal DEI plan in place, you will be in a position to continually assess and measure your efforts, identify and prioritize root causes of systemic inequity and barriers to change, and develop strategies to eliminate or mitigate root causes and barriers. Through these efforts, you will be set up to contribute to improving health outcomes for all who are impacted by rare diseases.

Learn how other nonprofit organizations have addressed Diversity, Equity, and Inclusion (DEI) Policies. Several NORD member organizations use the "DEI Template" developed by Bloomerang: <https://bloomerang.co/resources/templates/diversity-inclusion-and-equity-policy-template/>. This sample policy was designed for a small arts organization, but the language can be adapted to fit your rare disease organization's culture, mission, strategy, and policies. It should also be thoroughly discussed and reviewed by all relevant parties at your organization. A larger organization might have more policies and stipulations around diversity, inclusion, and equity than the small arts

Inequality
Unequal access to opportunities



Equality?
Evenly distributed tools and assistance



Equity
Custom tools that identify and address inequality



Justice
Fixing the system to offer equal access to both tools and opportunities



organization example used in this template. Your policy might be one page long or it might be several.

Explore what questions to ask and consider when creating a DEI Action Plan with this resource developed by the Council for Nonprofits: <https://www.councilofnonprofits.org/tools-resources/why-diversity-equity-and-inclusion-matter-nonprofits>.



Reflection for Nonprofit Leader

- *What is your organization's positioning around DEI? Discuss with your team where you fit on the [Inclusive and Equitable Organizational Development Continuum](#). What can you do to move toward becoming a fully inclusive, multicultural organization?*

Additional Resources from NORD

1. NORD DEI Webinar and Toolkit Series

Navigating DEI in Rare Disease Nonprofits

Webinar: bit.ly/Navigating-DEI-Nonprofits

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. Advancing Health Equity: A Community Conversation for Rare Disease Day

Webinar: bit.ly/Advancing-Health-Equity

3. ADA 508 Compliance and General Accessibility Webinar Tips

PDF: <https://documentcloud.adobe.com/link/track?uri=urn:aaid:scds:US:c82982f6-595d-4a09-8d46-1130f5bf4c87#pageNum=1>

4. DEI Case Studies from NORD's Rare Cancer Coalition

Video: <https://www.youtube.com/watch?v=hPzDP6jaSok>

5. Health Equity and Rare Disorders

Video: <https://www.youtube.com/watch?v=mPvHuunWzEU>

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, 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, 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.”² 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://smartgivers.org/nonprofits/diversity-equity-inclusion-toolkit/>
2. <https://www.integrativeinquiryllc.com/post/how-bias-influences-perception-three-lenses>
3. <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>
4. <https://friendsnrc.org/wp-content/uploads/2021/05/More-Than-Numbers.pdf>
5. <https://accessibleweb.com/web-accessibility-news/does-title-iii-of-the-ada-and-section-504-of-the-rehabilitation-act-of-1973-apply-to-our-nonprofit-organizations-website/>
6. <https://www.sps186.org/downloads/attachments/44633/Where%20I%20am%20From.pdf>
7. <http://www.accessibleuniversity.com/accessibility-basics/defining-accessibility>

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 330 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.