

# 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

# 2



## PART 2

### MEMBERSHIP INCLUSIVITY: WHO'S LEFT OUT? RECOGNIZING BARRIERS AND BUILDING AN INCLUSIVE COMMUNITY

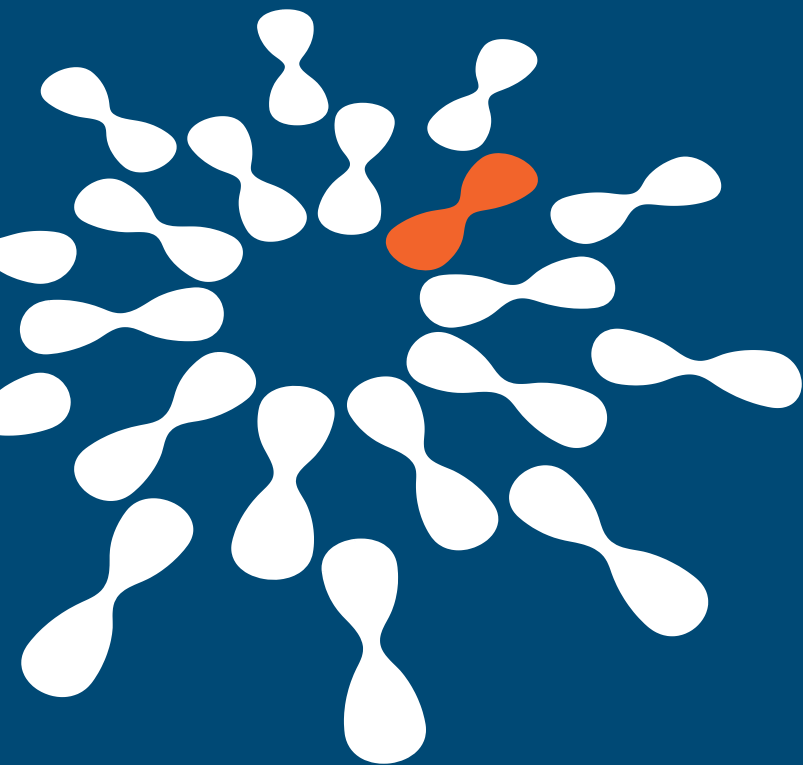


## PART 2

# MEMBERSHIP INCLUSIVITY: WHO'S LEFT OUT? RECOGNIZING BARRIERS AND BUILDING AN INCLUSIVE COMMUNITY

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# 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 rare 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

DEI requires more than just a conversation—it requires action. Organizations need to consider opportunities and best practices that foster the creation of inclusive and equitable spaces in the rare disease community. Inclusion speaks to the questions: Who is participating? Is everyone genuinely welcomed and able to participate in the conversation? Who is not participating and why? How can we improve? This second part of NORD's DEI webinar and toolkit series highlights current gaps in engaging marginalized populations within the rare disease advocacy space. We will discuss opportunities for us all to work together to bridge these gaps through active, accessible outreach and communication.

## Objective

This toolkit aims to help leaders of rare disease patient advocacy groups set goals and strategies for expanding the communities they serve, focusing on marginalized populations and authentic outreach and network building.

The toolkit will:

- Define key terminology related to DEI best practices.
- Provide worksheets and templates to develop DEI goals, strategies and community engagement plans.
- Share resources and further reading recommendations to explore these topics, including case studies of healthcare groups implementing diversity and inclusion practices.

## An Introduction to Inclusion

*“Being Black with cystic fibrosis means being misunderstood. It means being left out because approximately 5 percent of people with cystic fibrosis are Black. It means being an afterthought.”*

BOBBY FOSTER, PATIENT ADVOCATE, CYSTIC FIBROSIS FOUNDATION

Read his blog post: <https://www.cff.org/community-posts/2020-07/being-left-out-black-man-cf>

### Why expand the community you serve? Why focus on underrepresented populations and communities of color?

Historically marginalized groups, such as people of color, low-income Americans, and members of the LGBTQIA+ (lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, including other sexual identities) community, face greater barriers to accessing and receiving healthcare.<sup>1</sup> Research has shown that a Black and/or African-American person with a disability faces more barriers in healthcare than a white person with a disability. It is also widely proven that the health field discriminates



systematically against women, people of color, and the LGBTQIA+ community. 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.



### Reflection for Nonprofit Leader

- Do members of your rare disease community experience being misunderstood by the medical community? How does this impact their care, diagnosis time, and access to research and treatments?
- Does your organization struggle to reach specific groups of people living with the rare disease(s) you serve?
- Whether or not you live with a rare disease, have you felt misunderstood or like “an afterthought” in your family, at school or in your professional experience? Have you felt misunderstood or undermined as a part of your healthcare experience or your experience at work? How did this treatment impact your life?
- Which identities do you have that allow you a certain level of power and privilege in society? Think: How might others see me based on my identities and related stereotypes associated with groups that I belong to?



**Further Reading:** Learn how some healthcare groups are addressing diversity in their patient populations:

- Case studies from six hospitals across the country: [bit.ly/diversity-health-care](https://bit.ly/diversity-health-care)
- Barriers and Considerations for Diagnosing Rare Diseases in Indigenous Populations: [bit.ly/rare-Indigenous-populations](https://bit.ly/rare-Indigenous-populations)

## Take Action: Create a Diversity, Equity and Inclusion Statement

**Why** is developing a DEI and accessibility policy important for nonprofits? Creating this policy is a way for an organization to express how it values the importance of representation, inclusion and access, in all that you do. It makes space for the organization to provide language, structure and expectations related to their DEI roadmap. The roadmap will include the alignment of your statement with current policies, procedures and practices that may limit how you operationalize your goals. Your statement will be visible to your constituents and serve as a platform for ongoing DEI internal and external engagement.

**Who** on your team should be involved in creating this policy? Which people should be at the table? Here are some considerations, and they include people with unique perspectives unique to the structure of your organization:

- Who are the most vulnerable people in your organizations?
- What area per your patient demographics are you missing? For rare diseases, this can include physical disabilities, neurological disabilities, Amish and people of other underrepresented religions, rural patients and people of color.
- Who needs to enforce the policy? (Managers or human resources?).
- Who can assist with accessibility issues? (ADA,<sup>2</sup> IT, language access).
- Whose job is not as flexible and may need accommodations or support to attend meetings?
- Are community partners at the table?



**What** should you include in your policy? See these samples and then dive into the worksheets in this toolkit to help you develop a statement for your organization:

- Inclusiveness Case Statement: [bit.ly/sample-inclusive-statement](https://bit.ly/sample-inclusive-statement) (The Denver Foundation)
- Diversity Inclusion and Equity Policy Template: [bit.ly/DEI-policy-template](https://bit.ly/DEI-policy-template) (Bloomerang)
- Principles of Community: [bit.ly/principles-community](https://bit.ly/principles-community) (Virginia Tech)

# Worksheet: Goal Setting

Use this worksheet to set your goal and outline strategies. To sustain DEI work, organizations need to have a clear goal.

BRAINSTORM	
<p><b>Why do you want to focus on membership inclusivity?</b></p> <p>Consider why are you doing this work; why now, why your organization, why this community; and are there specific underrepresented communities that you would like to prioritize in your work? Why?</p> <p>A good goal is clear and inspires you to do the work for the long-term.</p>	<p><b>Goal:</b></p>
<p><b>What populations would you like to reach that you're currently not yet reaching?</b></p> <p>Perhaps you already have a clear idea of who these communities are. If so, list them here. If you need more guidance, here are some questions to get you there:</p> <ul style="list-style-type: none"><li>• Which communities are most affected by your rare disease?</li><li>• What are the demographics of the area(s) you serve?</li><li>• Which communities do you not yet connect with proportional to the demographics of your disease area?</li></ul>	<p><b>Populations:</b></p>
<p><b>What are some reasons/issues you are not already connected with these populations?</b></p> <p>Think about marketing, communications methods, staff considerations, board considerations, accessibility, location, language, and/or outreach strategies you currently use.</p>	<p><b>Reason/Issue:</b></p>

## Worksheet: Strategies

For each **Reason/Issue** listed, come up with a **Strategy** to address that. Some might be easy fixes, and some might be very complex. Don't be afraid to think big! Check out this [🔗 Diversity and Inclusion Strategy template \(bit.ly/sample-DI-strategy\)](https://bit.ly/sample-DI-strategy) as a starting point.

REASON/ISSUE	STRATEGY
Ex. Your community partners/networks are not diverse	<ul style="list-style-type: none"><li>• Join existing diverse coalitions and professional organizations</li><li>• Hold a virtual open house and partner with a more diverse organization</li><li>• Partner with a local university graduate school to explore possible internships(paid) and practicum students. (Ex. Most social work students have to complete practicums)</li></ul>

**Tip:** You can increase inclusivity by translating resources and materials into multiple languages. Translated materials is just a starting point, and you can do this with these budget-friendly possibilities:

- Translators Without Borders <https://translatorswithoutborders.org/>.
- Partner with similar organizations in your community that may provide shared resources and assistance.
- Partner with colleges and universities that may offer free services to local community organizations. Keep in mind that this is a brainstorming list, not a contract.

Organize the list of Strategies you come up with into: “Low Hanging Fruit,” (or easily attainable goals) “One-Year Goal,” and “Multiple-Year Project.”

“LOW HANGING FRUIT”	ONE-YEAR GOAL	MULTIPLE-YEAR PROJECT



**Further Reading:** Consider conducting remote clinical trials to reach more patients. Discover ways to make each step of your trial virtual or remote-access:

- Methods for Remote Clinical Trials [bit.ly/remote-clinical-trials](https://bit.ly/remote-clinical-trials)
- FDA’s Resources on Clinical Trial Diversity [bit.ly/FDA-Clinical-Trial-Diversity](https://bit.ly/FDA-Clinical-Trial-Diversity)
- Fact Sheet on Clinical Trial Diversity <https://www.fda.gov/media/106965/download>
- Diversidad En Los Estudios Clinicos (FDA) <https://www.fda.gov/media/106970/download>



## Worksheet: Community Engagement Plan

Create a community engagement plan. Pick which strategies you are most excited about and make a plan to address them. Some tactics to following through are:

- Establish a “Community Engagement Task Force” in the workplace to discuss projects and determine who will own projects.
- Set up recurring meetings to work on each strategy and to keep lines of communication open.
- Create a communication channel for each strategy (e.g., Teams chat, WhatsApp, Slack channel).

Create a list of action items for each strategy and delegate them to your team:

STRATEGY	ASSIGNED TO	ACTION ITEMS	DEADLINES	PROGRESS NOTES
Sample Strategy	Team Member	1. Action Item #1 2. Action Item #2	1. Deadline for Action Item #1 2. Deadline for Action Item #2	[Fill this out at each check in or meeting]
Strategy 1	Team Member			
Strategy 2				
Strategy 3				
Strategy 4				
Strategy 5				
Strategy 6				
Strategy 7				

For each **population**, research at least one community organization, neighborhood, community clinic, and/or community leader in the local community that you can connect with. One of the most important elements to effective community engagement is long-term relationship building.

Having trouble compiling the list? Try searching the web or check local publications online, searching keywords. Your new connections do not have to be medically focused, they should just have strong trust and influence within their community. You can also connect with your current patients, volunteers, and staff (e.g., with a survey) to identify touchpoints that they have in the community already, and whether they are open to community relationship-building.

**Tip:** “Meet people where they live.” It is best to meet your new connections in their neighborhood or space to provide an atmosphere that is safe, familiar, and comfortable for your new task force member, and to demonstrate your willingness to be equal partners. Try going to a community’s local event, offering to meet at their offices, or researching a nearby coffee shop where you may meet. While you are there, you can check out nearby businesses or organizations that could be your next contact.



**Further Reading:** Access to technology can be a significant barrier to connecting with certain communities. You may learn from your community that in order to “meet them where they are” and connect with these communities directly you will need to dedicate additional time, insight, and resources to creating print materials and even advertising through radio, TV or posters instead of online:

- Learn how [NORD engaged with the Amish community in Central Pennsylvania \(https://rarediseases.org/amish-community-testimony/\)](https://rarediseases.org/amish-community-testimony/) as part of a Patient-Focused Drug Development meeting with the U.S. Food and Drug Administration (FDA).
- Many media companies offer discounted advertising rates for nonprofit organizations.



## Worksheet: Building Partnerships and Coalitions

Establish a coalition of organizations or individuals to help achieve your goal, especially if your staff or team is small. Learn all the steps to creating a coalition from the “Community Tool Box” online resource [bit.ly/Community-Toolbox](https://bit.ly/Community-Toolbox), from the Center for Community Health and Development.

Relationships should be mutually beneficial. You are well versed in the benefit to your organization to develop these new relationships, now what is the benefit to them? Articulating that can make a community leader or organization more likely to engage with you and get excited about a partnership.

Benefits to a partnering organization:

**Example:** Opportunities to promote their programs via your social media and community channels can provide increased visibility for the organization

BENEFITS TO A PARTNERING ORGANIZATION
Benefit #1
Benefit #2
Benefit #3
Benefit #4

COMMUNITY	CONTACT NAME	ORGANIZATION/ TITLE	EMAIL	PHONE NUMBER



### Reflection for Nonprofit Leader

- Are you a part of any outside groups, clubs, or organizations? How would you like to be approached by an outside organization? What would make you feel excited to work with someone new?
- Are you currently collaborating with other nonprofit organizations, research institutions or industry/pharma companies? How did you initiate the partnership?



**Further Reading:** Go deeper into the steps toward eliminating disparities by reading these articles from nonprofit governance and social justice organizations:

- Transforming Our Sector by Dismantling Systemic Barriers, [bit.ly/Transforming-Sector](https://bit.ly/Transforming-Sector)
- How Does Racism Show Up In Nonprofit Work, [bit.ly/Racism-In-Nonprofits](https://bit.ly/Racism-In-Nonprofits)

### Email template for community outreach:

Dear [Name],

*I am a representative from [organization name]. We work with people impacted by [rare disease, and brief explanation]. I am reaching out to connect about ways that my organization may be able to partner with yours. We are working to engage with underserved communities in order to [articulate your GOAL here]. I hope we can collaborate on this mission.*

*We would love to come to your location to talk to your constituents and raise awareness about [rare disease]. Do you have an upcoming event that we may be able to attend and provide information? Or would you like to find a time to chat on the phone to discuss ways that we can team up?*

*Some of the benefits to your constituents may be [list BENEFITS]. We look forward to connecting with you further and finding ways to create a mutually beneficial partnership.*

## Additional Resources from NORD

### 1. NORD DEI Webinar and Toolkit Series

*Navigating DEI in Rare Disease Nonprofits*

Webinar: [bit.ly/Navigating-DEI-Nonprofits](https://bit.ly/Navigating-DEI-Nonprofits)

*Membership Inclusivity: Who's Left Out?*

Webinar: [bit.ly/Membership-Inclusivity](https://bit.ly/Membership-Inclusivity)

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

Webinar: [bit.ly/BOD-Diversity](https://bit.ly/BOD-Diversity)

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

Webinar: [bit.ly/Advancing-Health-Equity](https://bit.ly/Advancing-Health-Equity)

### 3. ADA 508 Compliance and General Accessibility Webinar Tips

PDF: [adobe.ly/3JprEkG](https://adobe.ly/3JprEkG)

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

Video: [bit.ly/DEI-case-study-NORD](https://bit.ly/DEI-case-study-NORD)

### 5. Health Equity and Rare Disorders

Video: [bit.ly/NORD-health-equity-webinar](https://bit.ly/NORD-health-equity-webinar)

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## Feedback

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

# GLOSSARY OF TERMS

## **A note about terminology for inclusion:**

*There are some ways of speaking about historically underrepresented communities that seem appropriate but may be insensitive, inaccurate or even off-putting for these populations. Did you know that by 2045, “minorities” will actually be a majority in the United States? In California, for example, there is no “majority” population and “Hispanics” or Latinx/a/os (of any race) are the largest single ethnic group in the state. The list of terms below may help guide you and others on your team who may not be aware of more appropriate terminology for engagement with diverse populations who you seek to include in your efforts. For more on inclusive language, browse this [one-page resource](#).*

## **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.”<sup>3</sup> 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.

## **Disability**

Impairment in a person’s body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss. Activity limitation, such as difficulty seeing, hearing, walking, or problem solving.<sup>4</sup>

## **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://bmcmredsmethodol.biomedcentral.com/articles/10.1186/s12874-021-01328-4>
2. <https://documentcloud.adobe.com/link/track?uri=urn:aaid:scds:US:2d892c0a-8c0e-4eb9-8bb1-c12402526922>
3. <http://www.accessibleuniversity.com/accessibility-basics/defining-accessibility>
4. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>

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.



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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