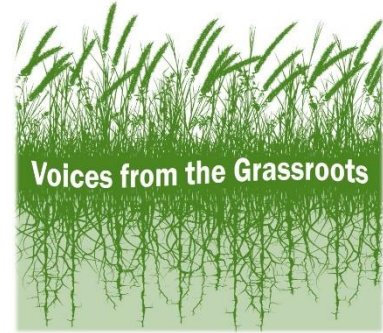


VOICES FROM THE GRASSROOTS COMMENTARY

## Research systems exploitation: The true cost to community-based organizations

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### Introduction

Community-based organizations (CBOs) are not sidekicks to institutional success. We are the organizers, translators, connectors, and problem-solvers that make outreach, public health, and crisis response work in communities that struggle. Yet throughout the documented past, we have been treated by universities, state agencies, and larger nonprofits as expendable infrastructure. We are valued for our access to trust, language, labor, and logistics, but left out of funding, decision-making, and credit. And for us, credit is not just about

recognition. It is how we build the visibility and leverage needed to secure future funding and partnerships.

This system is not accidental. It is designed to benefit institutions while keeping CBOs and those they serve compliant, invisible, resource-starved, and underfunded. Whether it is research grants, public health campaigns, pandemic response, or climate response dollars, our work shows up in outcomes and slide decks without our names, without our voices, and without our consent.

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### AI Use Declaration

Portions of this commentary were developed with assistance from OpenAI's ChatGPT, which was used to support the synthesis of concepts, editing for clarity, and organization of themes. All content was subsequently reviewed and revised by the authors to ensure fidelity to lived experience and alignment with community-based values and priorities.

## Background

Our CBO, North Carolina Focus on Increasing Education, Leadership, and Dignity (NC FIELD), began as a movement in 2009 when community organizer Emily (Drakage) Merletto, with the Association of Farmworker Opportunity Programs (AFOP) Children in the Fields campaign, arrived in the region to document the hundreds of children working in fields of tobacco, blueberry, sweet potato, and other crops. Child-serving agencies, local civically engaged attorneys, and farmworker parents and children began meeting, with the goal of elevating the fact that child workers exist, and that they need resources and protections. This group collaborated extensively with Human Rights Watch and lobbied at the federal level to expand the federal Fair Labor Standards Act (FLSA) to protect children on work crews in agriculture. In 2015, this collaborative advocacy resulted in the first-ever U.S. Environmental Protection Agency (EPA) Worker Protection Standards (WPS) minimum legal age to apply pesticides. As we have evolved, NC FIELD's mission has become to work alongside marginalized communities to build

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**Yesenia Cuello** is the executive director of NC FIELD, a community-based organization she co-founded as a youth in eastern North Carolina, prioritizing those working in the food supply chain. A former child tobacco worker and youth organizer, Yesenia assumed leadership at age 27. Since then, NC FIELD has substantially expanded its capacity through programs like evening mobile health outreach, application assistance, and culturally rooted food distributions in a mutual aid model. In addition, Yesenia is a certified alcohol and drug counselor and mental health first aid instructor, with a strong commitment to advancing bilingual and bicultural mental health and addiction access. She and her five siblings were raised in Pink Hill, North Carolina.

**Melissa Castillo** is a co-founder of NC FIELD and is currently the operations specialist for health access & equity at NC FIELD, where she leads grant writing, supports reporting, contributes to program development, and provides internal systems support. She is also a certified alcohol and drug counselor and mental health first aid instructor, bringing a trauma-informed lens to her work. A decades-long bilingual and bicultural farmworker ally from Appalachia, Melissa first engaged in activism as a child on the United Mine Workers of America (UMWA) picket lines. The granddaughter of a child coal miner who died young, she grounds her work in justice, dignity, and the lived realities of marginalized communities.

capacity, achieve holistic systems, secure equitable access to resources, and ensure a strong and inclusive rural North Carolina. We do this by focusing on community organizing, and by providing information, opportunities, and access to the infrastructure and other social determinants of health resources that people need to live healthy, happy lives.

Our CBO is routinely asked to join task forces and statewide networks, and we often join with the hope that the collaboration will eventually lead to additional capacity for the communities we represent. Historically, our participation is taken as blanket consent. The interaction feels like a partnership disguised as a transaction. There is no actual exchange beyond the “privilege” of inclusion. There is no funding, no agreement, no acknowledgment, and no credit for the data accrual and outreach we provide, or for our knowledge. However, declining to participate carries reputational risk, especially during a crisis. The pressure is often greater when there is a standing contract or subgrant in place. What we hope to be the basis for a partnership is almost always extraction. We give up our data for free, and the agency, university, or nonprofit claims the outcomes as its own, repeatedly, without source citation or investment.

Accepting symbolic partnerships and scraps from multimillion-dollar budgets perpetuates the same institutional extraction and marginalization that so many claim to oppose. In order to change this system, CBOs must send a clear message:

**If an agency or university or other institution wants to reach our communities, practices of extraction are not an option.**

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**Amy Elkins** is the Sembrando Salud coordinator and part of the administrative team at NC FIELD, where she supports community health workers and manages data systems, health outcomes, and logistics across multiple counties. Raised in a bilingual, bicultural household, she is a youth co-founder of NC FIELD and lifelong ally to farmworker families. Amy has built deep trust in the communities she serves. As the daughter of an activist, she spent her summers in agricultural fields, migrant labor camps, and playing tag in the dark with farmworker children—experiences that shaped her enduring commitment to equity, cultural competency, and community-rooted care.

## Keywords

predatory research, extractive partnerships, budget capture, epistemic exploitation, institutional review board (IRB) reform

## Our Definition of Terms

- **Predatory Research:** Using a CBO's labor, data, identity, or proximity to secure grants or publish findings without shared design, consent, or authorship; exclusion is built into the process by design. **Say our name.**
- **Budget Capture:** Fulfilling deliverables through a CBO's input, outreach, or materials without equitable budget allocation.
- **Epistemic Exploitation:** Expecting marginalized groups to provide insight without compensation or authorship as a way to legitimize institutional work.
- **IRB Cloaking:** Deploying vague consent as approved by an IRB<sup>1</sup> to gather data without transparency on the current or future use, including scope.
- **Post-Award Pretendship:** Naming CBOs only after funding is secured without shared planning or power; asking for favors or barely funding the implementation.
- **Resource Disparities:** Expecting CBOs to contribute significantly to projects without equitable financial compensation, leading to resource strains.

## A Common Pattern

NC FIELD has supported interviews, data-gathering, and outreach for funded efforts without knowing that grants were in motion or funded. One project funded for over US\$400,000 offered us US\$2,000 (later US\$5,000, after protest) for dissemination. We distributed U.S. Environmental Protection Agency (EPA) pesticide safety materials as a “favor” while other community-based organizations received millions in grant support. We also contributed to the development of a separate EPA

grant that ultimately resulted in that CBO situating itself as experts to the remaining CBOs by way of professional development activities, as opposed to contracts and subgrants for community organizing. We are asked for help to refer and organize without a contract or idea of how the work is supported. During crises, we coordinated responses used in state data reports with no citation at national conferences. We have co-developed training curricula and community-facing bilingual materials used in outreach and research, yet we are named only once as co-authors or contributors in the multiple resulting publications.

This is not random. It is a long-standing pattern involving universities, state agencies, and intermediaries. Philosopher Nora Berenstain (2016) calls this *epistemic exploitation*: when people in power expect communities like ours to do the work of explaining conditions we did not create, and then use that knowledge for their own gain, without recognition, authorship, or investment.

## Why It Happens

These practices persist because systems reward them:

- Grant frameworks require engagement, not equity.
- IRBs emphasize individuals, not organizational rights.
- Institutional timelines reward speed, not trust.
- Agencies act as fronts, while CBOs do the actual work, at the same time sacrificing documented expertise and leverage with larger funders.
- CBOs are expected to show good faith, while institutions operate with impunity.

## Recommendations

### *For Funders, Institutions, and IRBs*

- Ethics reviewers should monitor for patterns of inequity through the lens of “**budget capture**”

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<sup>1</sup> According to Wikipedia, “An institutional review board (IRB) ... is a committee at an institution that applies research ethics by reviewing the methods proposed for research involving human subjects, to ensure that the projects are ethical. The main goal of IRB reviews is to ensure that study participants are not harmed (or that harms are minimal and outweighed by research benefits). Such boards are formally designated to approve (or reject), monitor, and review biomedical and behavioral research involving humans, and they are legally required in some countries under certain specified circumstances” (“Institutional review board,” 2025, para. 1).

and “**epistemic exploitation**” to guide their assessments. These terms help flag situations where community partners are underfunded or where their knowledge is extracted without shared power or credit.

- Establish clear institutional practices that promote transparency and protect CBO partners in IRB processes and funding relationships, including advocating for their roles, rights, and resources.
- Flag grants with CBOs named but not funded or consulted. Strengthen IRB terms.
- Specify in writing how downstream use, authorship, and institutional affiliation will be handled beyond the life of the project. This should be documented through mechanisms such as memorandums of understanding (MOUs) or project agreements. Require shared authorship, narrative review, and oversight roles of the CBO partners, not a state agency or umbrella organization.

#### *For CBOs*

- Set authorship, consent, and funding terms (e.g., payment schedule, indirect cost allocations, reporting expectations), and demonstrate transparency around expectations for full partnership.
- Recognize that informal contributions such as quotes, conversations, site tours, and “feedback” are often documented in grant reports and publications as deliverables.
- CBOs should retain rights to stories, images, tools, and curricula they create or co-develop. This can be established through a written agreement (e.g., MOU or data use agreement) that clarifies ownership, attribution, and conditions for use. A practical and equitable solution is co-licensing: CBOs and researchers may both use


the materials, but any external publication, training, or replication requires mutual consent. This protects community integrity while allowing collaboration to continue in good faith.

- Staff and boards must understand IRB and grant systems, and refrain from personal interactions that involve sharing information about the CBO’s research or activities. This includes avoiding casual conversations where others seek updates, details, or personal opinions about its work, partners, or community members.
- Track and publicly report exclusions.

**Silence enables extraction.**

#### **Conclusion**

CBOs are the social systems that have the capacity to make local food systems and related environmental policies, health access, disaster recovery, safe housing, and broadband expansion possible. Without our insight and labor, none of these public wins are achievable—no matter how much research and how many millions of dollars in funds are invested. Yet, we are consistently erased from the tools we need to implement the work. Academic institutions and government intermediaries benefit from our trust networks and our ability to deliver, but avoid sharing the resources, power, or credit beyond the bare minimum. “Inclusion” as a symbolic gesture and our participation in systemic oppression as CBOs will continue to build the wealth of institutions and state agencies, not marginalized communities.

When institutions extract from CBOs to further their internal agendas while offering scraps in return, they are not solving an issue—they are perpetuating it. This is not a flaw in the system. **It is the system. The next step is not inclusion—it is structural change.** 

#### **Annotated Biography**

The following open-access sources informed this essay and speak to the real-world challenges that community-based organizations face in research partnerships. These readings offer grounded insights on authorship, funding, equity, and what it takes to build non-extractive collaboration.

- Berenstain, N. (2016). Epistemic exploitation. *Ergo: An Open Access Journal of Philosophy*, 3(22), 569–590. <https://doi.org/10.3998/ergo.12405314.0003.022>

Berenstain introduces the term *epistemic exploitation* to describe how marginalized groups are expected to share knowledge and explain injustice, while others benefit from their labor without recognition or return.

- Gaechter, L., & Porter, C. M. (2018). “Ultimately about dignity”: Social movement frames used by collaborators in the Food Dignity action-research project. *Journal of Agriculture, Food Systems, and Community Development*, 8(Suppl. 1), 147–166. <https://doi.org/10.5304/jafscd.2018.08A.004>

This article explores how different partners in a research collaboration framed their work using the language of dignity, power, and justice. It is useful for understanding where things break down between values and practice in academic partnerships, especially when it comes to voice, representation, and control over outcomes.

- Glassford, B. (2023). The peaks and valleys of connection—Lessons from Smart Village initiatives and supportive policies in the EU and UK for a Canadian context [Master’s thesis, University of Guelph]. The Atrium repository, University of Guelph. <https://hdl.handle.net/10214/27661>

Glassford’s research shows how rural communities in the UK and EU built their own infrastructure with real funding, long-term planning, and control over tools and data. It helped us think about what is possible here when funders work with us from the beginning (not after the fact).

- Porter, C. M., & Wechsler, A. (2018). Follow the money: Resource allocation and academic supremacy among community and university partners in Food Dignity. *Journal of Agriculture, Food Systems, and Community Development*, 8(Suppl. 1), 63–82. <https://doi.org/10.5304/jafscd.2018.08A.006>

This article lays out how grant funding often flows through universities, leaving CBOs doing the work without control over resources, timelines, or recognition. It mirrors what many of us have seen in symbolic partnerships.

## Reference

Institutional review board. (2025, May 25). In *Wikipedia*. [https://en.wikipedia.org/wiki/Institutional\\_review\\_board](https://en.wikipedia.org/wiki/Institutional_review_board)