*Action Notes*

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# NEEDED: Grassroots Leaders to Lead Systems Change Efforts that Reduce Infant Mortality

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## Abstract

The death of an infant devastates a mother, family and community. The United States has one of the highest infant mortality rates among the world's high income nations. Infant mortality is a key indicator of a population's health and societal well-being, yet interventions aimed at improving societal well-being are rarely a priority when devising infant mortality reduction strategies. Historically, grassroots movements have been critical in advancing social change to improve women's health and empowerment in marginalized communities. Understanding strategic and infrastructure elements of these grassroots movements is a critical first step to efficiently growing USA grassroots movements to address social systems associated with poor birth outcomes. We provide an analysis of the diverse array of grassroots structures and strategies utilized to improve maternal and child health outcomes. It is time for grassroots movements to form and be recognized as vital players in efforts to sustainably reduce infant mortality in the United States. It is essential to foster grassroots leaders and movements that improve long standing social structures that

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contribute to poor birth outcomes. The personal and community knowledge of these leaders and community members are desperately needed to save women and infants in our nation.

**Keywords**
community activism, women's empowerment, maternal and child health

## Personal Reflexive Statement

*Spending nearly 20 years working to improve birth outcomes in low income, marginalized communities across the United States has been a rewarding, humbling and frustrating experience. We have celebrated many births, learned far more from women in these communities than they have learned from us, and unfortunately, have experienced the deaths of too many babies. It is tragic that our nation continues to utilize the same intervention strategies to reduce infant mortality, even when we fail to see significant, sustainable reductions in marginalized communities. It is time to assertively address inequitable social systems that underlie infant mortality in these communities. This action needs leadership from women within these communities. These women know the social, economic, political, and environmental causes that underlie poor birth outcomes. They possess knowledge and wisdom regarding solution strategies to address these causes. We initiated a community-based leadership training initiative to train and mentor women from neighborhoods with high infant mortality rates to be grassroots maternal and child health leaders. Already within the first 18 months of our initiative, new social networks consisting of grassroots leaders and decision makers have coalesced to formulate new actions dedicated to saving babies by changing social systems.*

Infant mortality, the death of an infant before their first birthday, is a critical indicator of population health (CDC 2019a). Though infant mortality around the globe is understood to arise from social causes (Kim and Saada 2013:2299), addressing pertinent social causes are rarely a priority when implementing infant mortality reduction plans. Infant mortality continues to be treated as a health problem with a focus on health centers, home visiting programs and health behavioral intervention programs created for pregnant and postpartum women. Problems with this approach are exemplified in the US. While the US spends more on health care than any other nation in the Organization for Economic Cooperation and Development (OECD 2020a), it is ranked 32/35 for infant mortality among these nations (OECD 2020b). Furthermore, racial disparities in birth outcomes are a persistent problem in the US (Lu and Haflon 2013:13). It is critical to address the social, political, and economic systems of oppression of which infant mortality is a symptom. This necessitates societal level action from the people who have the most intimate understanding of these systems—the women themselves.

No one knows better the societal problems underlying poor birth outcomes than the women who live in communities persistently plagued by high infant mortality rates, yet their voices remain unheard, their knowledge underutilized. To understand details of the root causes of infant mortality and what solution strategies will work, it is essential that the voices of these women are amplified and their community knowledge utilized. There is no singular model approach that can improve birth outcomes in every area, the needs and challenges vary significantly even between communities in close proximity to one another. For this reason, it is imperative to understand the assets, needs, and characteristics of different grassroots approaches, as well as the characteristics of individuals who have successfully led them. Spreading knowledge of these approaches across communities and disciplines allows the facilitation of grassroots methodology to be used as a means to improve infant mortality rates and maternal and child health outcomes in general, even in communities that have not benefited from a grassroots movement. Grassroots movements are critical for driving change in economic, social, and political systems to create environments that provide the opportunity for all women to have a healthy pregnancy and all infants a safe, healthy and developmentally rich childhood.

## The Marginalization of Grassroots Movements

Grassroots movements have historically been the primary driver of meaningful, long-term community change for women's health issues. As scholar Beatrix Hoffman (2008) points out, "Although each movement had its leaders, each relied on grassroots participation . . . they were made up of ordinary people demanding reform, often on their own behalf" (p. S69). It was because women banded together in the 1970's that the first texts specifically covering women's health were created, and it is because of them that a National Women's Health Network exists today (Our Bodies Ourselves 2020). The foundation of women's health was built not by health workers or doctors, but by a community of women; they banded together to construct educational materials and petition legislators and doctors to pay closer attention to issues such as forced sterilization and unnecessary mastectomies (Norsigian et al. 1999:5). The needs these women addressed were not isolated only to the US. Their publications *Our Bodies, Ourselves (1969)* and the *Boston Women's Health Collective (1969)* were bestsellers both in the US and internationally, having been translated into Japanese, Russian, Spanish and a variety of other languages. For the first time, women's health was not being treated as some lesser-important offshoot of men's health, but rather as its own field.

The history and importance of these movements are easily overlooked because of how often women's health initiatives are discussed only in terms of elite-led healthcare reform, or in terms of larger paid-staff nonprofit organizations (Smith 1997:2). The conventions surrounding NGO-based literature add to this issue; grassroots organizations are often seen as the "dark matter" of the nonprofit world, impossible to study or understand (Smith 1997:1). Smith argues that NGO literature that

completely excludes grassroots associations is "incomplete, distorted, and misleading in systematic ways" because excluding grassroots associations implies that these associations are either nonexistent or unimportant (Smith 1997:1). Smith estimates that grassroots associations make up around 90 percent of the nonprofit sector, yet they remain the least studied portion of it (Smith 1997:7). Due to this lack of literature surrounding grassroots movements and organizations, successful strategies implemented by grassroots leaders remain poorly understood and underutilized.

Another potential reason for the exclusion of grassroots literature from NGO literature is that these organizations tend to focus more on meeting community needs than they do on collecting data to prove their effectiveness. When women are treated as "a person, not a statistic" (World Wide Fistula Fund 2020), this works out well for the women and less well for statistics. Ideally, organizations should be able to collect good data and empower women, but the limited size of many grassroots organizations makes this difficult. For grassroots initiatives whose main focus is on serving immediate community needs, and not on articulating research, it can be difficult to find the time and resources to keep good records of their impact, or to record the strategies they used.

## The Diversity of Grassroots Approaches

Our review seeks to uncover strategies used by women grassroots leaders and illuminate how these strategies may be utilized on a larger scale to provide "intentional and careful support" to assist and encourage "indigenous processes of empowerment" (Wrigley, Marshall, and Sarbanes 2018:23). For this reason, we researched the strategies and structures utilized by a multitude of different organizations all over the world that advance maternal and child health efforts at a community level and establish community-led, woman-centric, sustainable leadership systems. We observed a diversity of grassroots movements in terms of their complexity and structure, and we discovered that different types of grassroots leadership aimed at improving birth outcomes for marginalized communities will need to be fostered and empowered to create sustainable improvements in infant mortality.

We emphasize the importance of a grassroots approach in whatever form it takes; the adjective "grassroots" is far more essential than whatever noun comes after it. Literature about grassroots initiatives discusses both associations and organizations. Smith defines grassroots associations as "locally based, basically autonomous, volunteer-run, formal, nonprofit groups that have an official membership of volunteers" (1997:3). He acknowledges that many of these associations are only semi-formal, and often lack the structural integrity of larger, more well-known organizations (Smith 1997:3). The main distinction between an association and an organization lies in its size; when defining the term "grassroots organization," nonprofit scholar Jo Anne Schneider writes that "[N]ot all 'grass roots' organizations lack formal governance structures and paid staff. Nor do all 'evolve' from informal meetings of like interested parties to Webarian bureaucracies" (Connectbrevard.org

2011). The natural history of these movements can be dynamic and influenced by numerous internal and external variables. For example, Our Bodies Ourselves has occupied a multitude of identities within the grassroots association/organization continuum. They started off as a small, informal association, but as their publication gained popularity, they grew into a larger non-profit organization while retaining their original grassroots leadership. For years, they functioned as a large non-profit with paid staff, but they had to scale back their organization in April 2018. Now, they are back to being a volunteer-led association with two main focuses: "advocating for women's health and social justice" and "providing limited technical support to OBOS's global partners" (Our Bodies Ourselves 2020). Ultimately it is not the size, structure and scope of a grassroots association/organization that provides its value, but rather the multitude of ways it meets the needs of a community (or communities). In terms of working with communities to apply a grassroots approach to improving birth outcomes, understanding the diversity of grassroots approaches will help community members better understand the type of leadership structures needed to foster the desired grassroots approach and cultivate a diverse array of partners.

An organization like Rural Women's Social Education Centre (RUWSEC), for example, has self-identified as a grassroots organization since its inception and continues to sustain movements by and for its community. It was founded in 1981 by a team of 13 women, 12 of which were Dalit, in the Kancheepuram District of Tamil Nadu, and remains a non-governmental agency (RUWSEC 2020a). Since their inception, RUWSEC's mission has been to promote women's agency over their bodies, reproductive rights, and gender equality through developing leadership among Dalit women (RUWSEC 2020b). The scope of their work has increased dramatically since the organization was created; in the beginning, their aim was to support "rural poor women" in gaining the tools they needed to "analyze the socio-economic and political factors underlying their lack of good health and control over their sexuality and fertility." Their scope has expanded to encompass field programs, reproductive health clinics, and publishing research. However, because all of these initiatives are led by and for the community that RUWSEC is based in, the increased scope of this organization does not discount its grassroots status.

Some initiatives may start as grassroots organizations but end up transitioning to larger multisector NGO's or multi-ministerial governmental organizations, particularly if there was a gap in the larger public sphere for their focus area. Mothers2-mothers is a great example of this. This organization was started by a man out of the trunk of his car in Cape Town, South Africa because he realized that there was a major issue with HIV—especially transmission between mothers and their children (Mothers2mothers 2020a). Now, the organization has reached over 11 million women and children and created over ten thousand jobs, and has expanded their impact to nine different countries in sub-Saharan Africa (Mothers2mothers 2020). The founder, Dr. Mitch Besser, now occupies a drastically different role in the organization than he used to; he went from being the organization's only employee

to working as part of a Senior Management team. This organization was able to grow to this scale across sub-Saharan Africa because the need to prioritize mothers with HIV/AIDS was great and was not being addressed to the extent needed.

Grassroots associations that focus on a particular maternal and child health issue often also realize other community needs, and may choose to partner with larger corporations or nonprofits to gain access to resources meet the diverse array of their constituents (Wesley and Dublon 2015). The Association for Rehabilitation and Re-Orientation of Women for Development (TERREWODE), is a great example of this. TERREWODE was founded in 1999 in the Teso sub-region of Uganda by women in the community, led by Alice Emasu and a group of women in the community (TERREWODE 2017a). The organization's focus is obstetric fistulas, which it addresses through awareness and advocacy, prevention, treatment, and the social reintegration of women into the community after their fistulas are treated. Since its inception, the organization has expanded its holistic approach to serve women with fistulas in the eastern, northern, northeastern, and central areas of Uganda, which was made possible by its many partnerships; their website lists thirty-two organizations with which it is partnered, including both NGOs and governmental organizations (TERREWODE 2017b). However, despite its drastic increase in size, Emasu remains the organization's president, and the fistula hospitals make an effort to employ women who have incurable fistulas and cannot undergo a full social reintegration. By approaching obstetric fistulas in a holistic way and involving the support of outside organizations, TERREWODE is able to fill a multitude of needs in the communities that it serves. Even though its geographic outreach has grown, it remains controlled and led by community women who are passionate about preventing and treating obstetric fistulas.

We also discovered that there are two main interrelated types of grassroots "missions" contributing to women's health movements. There are grassroots approaches that work inside the community in need, and there are grassroots approaches that operate as fundraising organizations based outside of communities in need, but still work to serve these communities. Both of these organizations do important work in promoting long-term women's and family health, grassroots leadership development, and community capacity building. While our focus is on grassroots women's organizations that work inside communities, we recognize and honor those external to communities in need that work as fundraisers. These organizations play an essential role in the provision of resources that provide for education and team-building necessary to expand community capacity. For example, the African Women's Development Fund (AWDF), started in 2001 by three African women, seeks to gather funding and distribute it to women's grassroots movements and organizations that need support (AWDF 2020a). The organization is run "for, by, and with African women," and focuses on providing the necessary funding, leadership, and other resources needed to help existing movements (AWDF 2020b). By both their definition and ours, AWDF is a grassroots organization. The intimacy between these external fundraising organizations and the community-led grassroots organizations they champion challenges the

notion that grassroots organizations built for and by a particular community are the only type needed to advance health equity for women.

The number of approaches used by grassroots initiatives to improve birth outcomes are as varied and multidimensional as the communities they serve. We thoroughly studied the literature on grassroots movements, community leadership development and community engagement, and studied the history, activities and successes of grassroots movements that have positively changed maternal and child health outcomes while advancing social change. Based on our review we developed an understanding of themes observed across successful grassroots initiatives aimed at improving maternal and child health outcomes. We organized these themes into four recommended key elements that can be applied by grassroots initiatives focused on changing social systems to improve birth outcomes. Though we have named and structured these four key elements, they were not invented by us; they were identified within the grassroots movements and organizations that we studied, put into practice in our local communities, and distilled into a structure from which public health workers, legislators, and existing organizations can benefit. Though we've undertaken the job of recognizing and compiling these four key elements, they exist thanks to the ongoing labor of a vast number of communities and community leaders across the world, both past and current.

## Four Key Elements of Grassroots Initiatives to Improve Birth Outcomes

### *A. Navigating across the Social-ecological Model (SEM)*

The social ecological model (SEM) of health promotion illustrates that addressing any health issue requires strategies at individual, interpersonal, organizational, community, and public policy levels. Approaches to birth outcomes that are solely grounded in the healthcare of individuals, or solely focused on changing healthcare delivery public policy, fail to utilize the critical, sustaining power that community engagement and social networks have to effect change. Grassroots initiatives are important for advancing sustainable improvements in birth outcomes because they start at a community level, in conversation with members of the community who have an intimate understanding of the barriers preventing healthy pregnancies and infants. We are far from the first to redefine women's health "through a structural paradigm"; Alicia Yamin has written at length about acknowledging the "social, political, and economic power structures" that shape the structural limitations placed on women, impacting their health (1997:169-70). Growing interventions from the community level allows navigation bidirectionally within the SEM (Figure 1). Mobilizing grassroots leaders to work across levels of the SEM facilitates meaningful changes at each level.

Efforts to improve birth outcomes have historically focused either on healthcare policy or on women's behavior—interventions that occur from the top or the bottom of the SEM. However, there are factors that affect birth outcomes that run far deeper

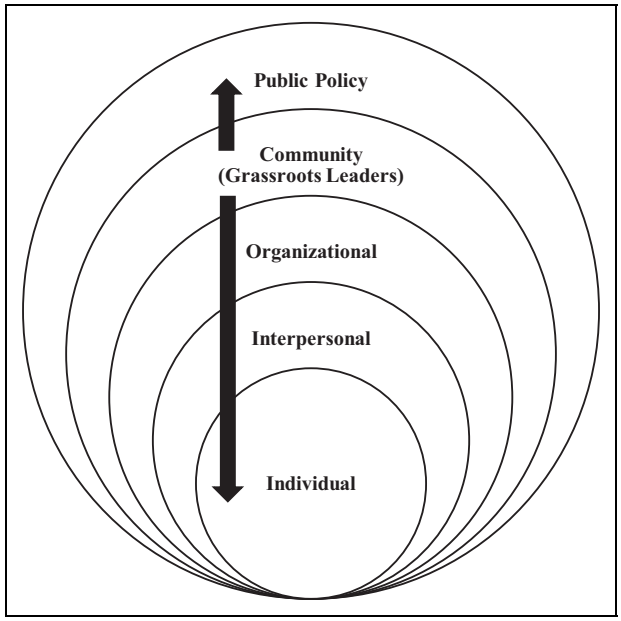


**Figure 1.** Grassroots leaders emerge from the community level to bidirectionally navigate the social ecological model of health promotion. Their lived experiences provide them with an expertise in the social structures that impact their community, and thus bring relevant issues and associated solutions to policy makers. Simultaneously, their community connections equip them with knowledge of organizations, families and individuals within their community and their respective priorities. The social ecological model for health promotion is adapted from McLeroy et al. (1988).

than the birth, delivery, and care of an infant. Many women face heath disparities as a result of the combination of multiple marginalized identities (Williams and Sternthal 2010). According to the CDC, Black women face pregnancy-related risk at a rate that is three to four times higher than that of white women (CDC 2019b). Geographic, socioeconomic, and racial inequalities combine in a variety of ways to create pockets of poverty where infant mortality rates are the highest (Freudenberg, Pastor, and Israel 2011). The effects of these systems of oppression are so pronounced that in the US, someone's zip code is a far better predictor of their health outcomes than their genetic code (Hickman 2015). Efforts to address infant mortality from either the top or the bottom of the model isolate infant mortality as a problem to be solved on its own rather than a product of larger social causes.

Interventions that occur at an individual level stop with that one individual, and may not even affect any notable, sustainable social, economic or environmental change in that person's life. Individual-level interventions rarely recognize that communities under stress (i.e. those at risk for high infant mortality) face "complex, multifaceted, and institutional problems" that prevent people from having the

resources to "mobilize and sustain efforts to address the multiple challenges they face," meaning that even if the people know what healthy choices they should be making, they still may not have the resources necessary to make those choices (Wrigley et al. 2018:22). For example, intervening simply to educate a mother about how to correctly care for an infant assumes that her lack of knowledge—and by extension, infant mortality as a whole—is an individual-level issue. However, in reality, social determinants such as rural living and high poverty remain associated with increased infant mortality rates "independent of individual maternal sociodemographic, health and obstetric factors" (Mohamoud, Kirby, and Ehrenth 2019).

Approaches to improve birth outcomes that focus on individual healthcare are often unaware of and fail to address the social determinants of health (Braveman and Gottlieb 2014:19). In the words of UNICEF, "While low-cost, low-technology, and high-impact preventive and curative interventions such as vaccines, antibiotics and micronutrient supplementation save lives, they are not enough for long-term, sustained impact" (2010). This is not to say that access to proper medical care is unimportant: rather, that medical care is far from the only influence, particularly over social systems that determine which people are more likely to "become sick or injured in the first place" (Braveman and Gottlieb 2014:20).

Looking at the US health care system as a whole, lower education levels/economic class in the US are directly responsible for more deaths relating to "preventable mortality" than medical care: medical care may affect as few as 10 percent to 15 percent of preventable deaths in the US (Braveman and Gottlieb 2014:20). The US spends substantially more on health care than any other country, but US residents still have access to less resources than residents of countries that spend much less money (John Hopkins University 2019). A 2017 study finds that the US has the lowest-performing health system of any high-income country and ranks the US as last in "access, equity, and outcome" (Schnieder et al. 2017:5-6). The US healthcare system is proof that putting money into a healthcare system is ineffective at sustainably addressing issues such as infant mortality, which have social factors as a root cause.

Top-down movements that come from the opposite end of the SEM can be equally ineffective as individual-level interventions, particularly when these efforts are focused only on health care. Any policy, healthcare or otherwise, that is not informed by the community it serves is in danger of being completely ineffective. For example, if politicians elect to eliminate a food desert by building a new grocery store, but fail to consider people reliant on mass transit systems, thousands of dollars could be spent on an endeavor that doesn't support the community in question. Because grassroots efforts grow from the community and relationship levels, they have a deep understanding of the social systems that influence birth outcomes, ensuring that federal and NGO funding is directed to areas that will best benefit birth outcomes.

For these reasons, grassroots community-level initiatives have the potential to effect change in ways that other efforts do not. Grassroots community-level efforts have the potential to spread upward or downward within the social-ecological

model, thus effecting change at each level. This approach eliminates the shortcomings inherent to either a top-down or bottom-up approach, laying the foundation to build something sustainable that can effect change from within the oppressive systems in which the community exists. For infant mortality, this means not assuming that it's a problem confined to health systems alone, but rather working to drive system changes that will create environments that support healthy pregnancies and infant development. A powerful example of this approach can be observed in the Rural Womens Social Education Centre (RUWSEC 2020a). This organization has implemented programming to address individual needs (Reproductive Health Clinic), relationship needs (Gender Sensitization Workshop for Men), organizational needs (Life Skills Education Workshops for Company Workers), community development needs (Creating a Training Manual for Community-Based Sexual and Reproductive Health Programmes for use by grassroots organizations) and social policy needs (Advocacy for Sexual and Reproductive Rights for Adolescents and Women, and Prevention of Intimate Partner Violence Against Women).

## *B. Harnessing the Power of Communal Storytelling*

One impactful way that grassroots leaders begin to affect change bidirectionally within the SEM is by telling the stories of themselves and their community. Storytelling has two main purposes in grassroots initiatives: 1) inspiring people outside of the community to act, and 2) establishing strong communication networks that form the foundation of sustainable leadership structures within communities.

Research indicates that data alone may be less effective at inspiring people to act than hoped. Psychological studies show that "numerical representations of human lives do not necessarily convey the importance of those lives," and that individual stories motivate people to act far more than statistics do (Slovic 2010:86). Perhaps this is why so many interventions have been made at an individual level: it simply makes better news stories, and conveys a positive and inspirational message even when nothing has changed at a societal or even a community level. However, the power of the *individual* narrative can also be harnessed to advance community initiatives. In the hands of capable grassroots leaders, storytelling has the ability to move upward within the SEM to effect policy-level change. Edna Adan, founder of the Edna Adan Hospital Foundation in Somaliland is a great example of this; her narrative of starting the organization is incredibly compelling, both in content and delivery, and has been used to great effect in reducing female genital mutilation (FGM) in her country (Edna Hospital Foundation 2020). She is one woman whose individual story of FGM *is* a story of her community's relationship to FGM; however, it's the narrative of her individual actions and experiences that inspires people to help rather than the numerical representations of her community's needs. Mothers2mothers also uses this technique; their website features a picture and a testimonial from a woman who was helped by their program and then went on to become employed by them (Mothers2mother 2020a.). By including her individual

story on their website, Mothers2mothers is putting a face to these abstract numerical values; in the audience's eyes, the women helped by the organization are no longer nameless, faceless women, but rather women like Wilbroda, one of the women featured.

Storytelling also fosters communication within communities. Women's silence has been "a dominant metaphor used to refer to women's marginal positions" in almost every culture, and storytelling breaks that silence (Pigg 2013b:40). Almost every culture has some oral storytelling tradition to fall back on, and reestablishing these cultural roots can help to build connection and trust within marginalized communities. Indigenous Studies scholar Dr. Malea Powell (2002) conceptualizes marginalized groups as existing outside of the purview of "dominant narratives," which she defines as narratives that "attain dominance through imagining themselves whole in contrast to other narratives" (p. 12). Powell (2002) suggests that marginalized communities can combat the harmful effect of these narratives by imagining themselves in "a different relationship to" them, instead centering stories and ideas from within the community (p. 18). Powell (2002) refers to this rebuilding of a community's cultural roots as telling "ghost stories"—grabbing onto the cultural roots that are still there and using them to reconceptualize what the community is and could be (p. 12). Grassroots leaders can set this narrative-based approach into motion through the use of positionality stories, positioning themselves as figures "with, rather than of" authority (Cedillo and Bratta 2019:218). This allows the leaders' life experiences within the community and their leadership training to become things of equal importance, and allows grassroots leaders to speak from and about their identity positions (Cedillo and Bratta 2019:218). The meanings of these stories are relational, working to both foster community members' trust in the leaders and to encourage the leaders to stay connected with and hear the needs of their community members. Strong communication helps to strengthen a community's ability to work together, helping everyone to believe in and contribute to the changes that the community hopes to make.

### *C. Building Leadership Structures to Support Collective Efficacy*

Community members that feel connected to and trust each other are able to harness the power of collective efficacy, allowing them to move toward a single goal for the common good. Psychologist Albert Bandura defined collective efficacy as "a group's shared belief in its conjoint capability to organize and execute the courses of action required to produce given levels of attainment" (Bandura, Freeman, and Lightsey 1999:477). Successful grassroots movements have collective efficacy as the backbone of their work: a community's participation is viewed as "both a dimension of and a condition for social change" (Riaño 1994:11).

Supporting impactful communication strategies of grassroots leaders is critical to building collective efficacy, as their communication will help to facilitate connections between community residents, as well as between community and outside networks.

For community-based grassroots efforts, it is essential to see leaders as based solely in community, not as some separate formal organization: the leaders and followers should influence each other (Pigg 2013a:13, 21). Some communities in need of intervention may have existing leadership structures, and some may few to none. In communities under great stress, personal connections are often "fragmented and divided by politics, economics, geography, and access" (Weaver 2019:251). That being said, it also doesn't make sense to establish community leaders and expect them to suddenly understand how to effect change within their communities just by virtue of assuming that role.

One person cannot hold all of the "skills, connections or solutions" that a community needs in order to effectively work toward a common goal (Weaver 2019:248); in the words of Alicia Yamin (1997), "interdisciplinary efforts will be needed to develop innovative institutions, procedures, and indicators" to address issues such as infant mortality in a way that tackles the effects of oppressive social systems (p. 173). Multi-sector collaboration in grassroots initiatives is vital; just as grassroots organizations partner with outside fundraising organizations, different members of a grassroots community effort will have different leadership abilities, skills, and perspectives to contribute.

Even someone like Edna Adan, with all of her many different kinds of training and experience, needed to utilize a more collective knowledge-base than she alone could give. Adan's organization has expanded in ways that her own initiative alone could not have supported, including the Edna Adan University, which offers a wide array of courses and specialties (Edna Hospital Foundation 2020). Mothers2mothers has also expanded drastically since its inception, but what makes Mothers2mothers unique is the fact that it was started by a man, Dr. Mitch Besser, who was not a part of the community of women he sought to uplift (Mothers2mothers 2020a). However, he listened to the community and realized that peer-to-peer interaction was necessary to sustain the movement, so he employed former patients within his program to become mentor mothers. Even if the initiative's very inceptions couldn't be defined as grassroots, it certainly is a grassroots organization now; Dr. Besser built something that is run by and for the community in which it's based. He also chose to include co-founders who had very different skill sets than his own, and could focus mainly on fundraising and building infrastructure, meaning that his own focus could remain on medicine (Mothers2mothers 2020b). Adan's and Besser's success exemplifies the fact that strong leadership comes from "the creation of a common purpose" between leaders and followers as they move together toward their shared goal (Pigg 2013a:18). This common purpose cannot be only one person's vision, but rather a collaboratively-crafted purpose that will mobilize a community to act.

Conceptualizing leadership as "relationships" rather than associating it with "positions or responsibilities" can help community members and leaders feel more comfortable with a new leadership structure (Pigg 2013a:20). By investing in the innate leadership and power of a community's leaders, it becomes possible to make a sustainable change in a community beyond the direct support of an individual

organization. Essentially, "neither community nor leadership exist without actions to create them" (Pigg 2013a:20).

There is a need to broaden perspectives of leadership "beyond an organizational context" and to "appreciate the distinctiveness and range of leadership styles best suited to a community change context" (Weaver 2019:251). Though there is no "one size fits all" approach, leadership for a community change context is inherently different from civic or organizational leadership, because the construction of power works differently (Weaver 2019:252). Because community-based initiatives require leadership to be conceptualized relationally, there can be no one ideal type of leader. The leaders of an initiative should ideally already hold some position of respect within the community, but more important than that, their skill sets should complement each other. This will allow them to most effectively navigate bidirectionally within the SEM, and to build the strongest possible team to make change happen at every level.

## *D. Empowerment as a Process, Not a Product*

All of the grassroots organizations we studied mention empowering women as one of their main goals. Everyone seems to agree that empowered communities are good and necessary, but scholars have defined empowerment in a multitude of ways. At an individual level, empowerment can be understood as an individual's ability to "grasp the information learned" and apply it to their daily lives: for example, implementing safe sleeping methods, proper nutrition, and other practices that reduce the risk of infant and mother mortality (Riaño 1994:8). But a mother's ability to put these things into practice relies not only on her understanding of the material but on whether or not she has the resources to implement them. For this reason, empowerment can be seen as something constructed from the two "inter-related dimensions" of resources and agency (Pigg 2013b:34). Expand this idea out to the community level where grassroots movements take place, and empowerment refers to "the individual and collective capacity and right to transform and affect change" (Riaño 1994:12).

In practice, a community's "capacity to affect change" can be hard to measure because community empowerment is something to be worked both toward and within. Framing it in more concrete academic terms like "social capital" and "collective efficacy" can give us the language we need to understand empowerment as an essential resource, but this terminology doesn't give us a way to take a concrete measurement. In reality, it is more productive to see empowerment as an ongoing process rather than as a product. There will never be a point when "empowerment" can be checked off of a list; it's always shifting and growing along with the community's needs.

Additionally, while grassroots community movements are capable of producing impactful long-term change, the capacity of these moments to effect change is "limited because of the framework that they too are confined within." (Wrigley

et al. 2018:23). Waiting for the oppressive framework that surrounds a community to change is not an option: for example, RUWSEC in South India works to empower impoverished women to advocate for their own health and well-being, but they are unable to dismantle the caste system that perpetuates this sort of poverty (RUWSEC 2020a). Being unable to change these larger frameworks of oppression is not a reason to resist involvement with communities of women in need of support: RUWSEC has changed a lot of lives, and has built a sustainable sense of empowerment in the community that will continue to facilitate this sort of work.

Focusing on the process of empowerment more than the outcome is an imperfect system, particularly because people want "specific changes" and "concrete improvements in social and material well-being" (Pigg 2013a:26), but it's simply the reality of working to uplift a community that exists within an oppressive structure. When the frameworks of oppression in place have no designated end date, it is essential that the community's sense of empowerment also has no end date.

## Conclusion

The word "grassroots" is used to describe a wide variety of organizations and initiatives, but at its core, a grassroots methodology is committed to working within the community in which it's rooted. Grassroots initiatives are never static entities—they work within larger networks of organizations, evolving with the needs of the communities in question. Some initiatives work to secure funding, while others work directly inside the communities, but regardless of their origins or the services they provide, all grassroots structures center the needs and voices of their communities. This often includes strengthening existing leadership structures or building new ones, enabling the movement to be sustained by the community itself, promoting long-term change. Our review of literature about grassroots movements, community leadership development and studying the history, activities and successes of grassroots maternal and child health movements across the globe revealed four key elements that grassroots initiatives and their leaders can adopt to advance societal change for improved birth outcomes.

Even though grassroots initiatives have historically promoted long-term community change in a way that few other efforts could, they continue to face a multitude of barriers far beyond the purview of what other types of initiatives face. Grassroots initiatives can have a harder time making themselves visible, which by extension means that it's harder for them to secure funding, prove the legitimacy of the work that they do, and articulate the strategies they use. This paper is an effort to begin closing this gap; there is little overlap between the authors of information about organizations we studied and the authors of the leadership strategies we surveyed. We believe that there is a key need for a curriculum articulated by grassroots leaders about their specific techniques, outcomes, and learning objectives, and we hope that this paper both highlights these needs and provides a foundation from which such a

curriculum might be constructed. This would benefit not just grassroots leaders, but any organization or initiative that works directly with communities.

Building infrastructure at a community level means training and mentoring grassroots leaders to become skilled in understanding health outcomes and social data, helping them learn the skills they need to effectively articulate the struggles they are facing to each other and to policymakers, and laying out their solution strategies across the SEM as community experts. To help support the training of local grassroots leaders passionate about infant mortality reduction, a university–community partnership recently created a grassroots maternal and child health leadership training curriculum, grounded in national maternal and child health leadership competencies (Skinner et al. 2019). This curriculum helps grassroots leaders to navigate bidirectionally within the SEM, with their work originating from the community level. It is from this level that they can move downward to effect change at relationship, organizational and/or individual levels, and/or move upward to articulate the needs of their communities into policy proposals.

This reconstruction of the SEM navigation forms the first of our four key elements of grassroots initiatives, and serves as the foundation for the other three. These four key elements serve as a starting point for grassroots leaders to articulate the grassroots structures that they have used as well as for other initiatives to understand and utilize grassroots methodology. At its core, these four key elements are tools that can be used to encourage meaningful community-level interventions. This starts with hearing and amplifying the voices of marginalized communities, and eventually transitions into building structures that allow this amplification to have a systems impact that can continue in a sustainable manner. These four key elements are less of a how-to guide and more of a starting ground: every community is different, but every birth outcome-related intervention must start with and be sustained by that community.

We particularly want to emphasize that these four key elements were truly extracted from global experiences, and that the US is included here. In the US, mothers and babies also find themselves trapped within a system that is flawed in systemic ways. Grassroots initiatives can work within these systems to create positive change, as exemplified by the impact of Our Bodies Ourselves movement on women's health education. The United States is in need of widespread grassroots movements that target infant mortality in a holistic way. We should be looking to the ways communities all over the world have tackled this issue without making a harsh distinction between the approaches taken within high and low income nations. Many of the leadership techniques used in successful grassroots initiatives can be adapted for the specific needs of a community.

Any sort of organization or initiative can use grassroots methods to effect change, starting by listening to members of the community to understand the social and economic causes of a problem. Communities know what they need, and an investment in understanding and sustaining community-led movements *is* an investment in reducing serious social issues like infant mortality. Locating, funding, and

platforming these communities improves the quality of the lives trapped within systemic problems, and forms the foundation for changing these systems.

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