

ENGAGED for CHANGE: A Community-Engaged Process for Developing Interventions to Reduce Health Disparities

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Abstract:

The science underlying the development of individual, community, system, and policy interventions designed to reduce health disparities has lagged behind other innovations. Few models, theoretical frameworks, or processes exist to guide intervention development. Our community-engaged research partnership has been developing, implementing, and evaluating efficacious interventions to reduce HIV disparities for over 15 years. Based on our intervention research experiences, we propose a novel 13-step process designed to demystify and guide intervention development. Our intervention development process includes steps such as establishing an intervention team to manage the details of intervention development; assessing community needs, priorities, and assets; generating intervention priorities; evaluating and incorporating theory; developing a conceptual or logic model; crafting activities; honing materials; administering a pilot, noting its process, and gathering feedback from all those involved; and editing the intervention based on what was learned. Here, we outline and describe each of these 13 steps.

Keywords: health disparities | community-engaged partnership | intervention

Article:

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ENGAGED FOR CHANGE: A COMMUNITY-ENGAGED PROCESS FOR DEVELOPING INTERVENTIONS TO REDUCE HEALTH DISPARITIES

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The science underlying the development of individual, community, system, and policy interventions designed to reduce health disparities has lagged behind other innovations. Few models, theoretical frameworks, or processes exist to guide intervention development. Our community-engaged research partnership has been developing, implementing, and evaluating efficacious interventions to reduce HIV disparities for over 15 years. Based on our intervention research experiences, we propose a novel 13-step process designed to demystify and guide intervention development. Our intervention development process includes steps such as establishing an intervention team to manage the details of intervention development; assessing community needs, priorities, and assets; generating intervention priorities; evaluating and incorporating theory; developing a conceptual or logic model; crafting activities; honing materials; administering a pilot, noting its process, and gathering feedback from all those involved; and editing the intervention based on what was learned. Here, we outline and describe each of these 13 steps.

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The development of individual, community, system, and policy interventions is difficult, and the science behind intervention development remains largely underdeveloped. Little guidance exists in terms of strategies and processes to translate community and population needs, priorities, and assets; qualitative, quantitative, or mixed-methods formative data; and theory into an intervention. There is a profound need for evidence-based strategies to demystify and guide the development of interventions (Bartholomew, Parcel, Kok, & Gottlieb, 2001; Hoddinott, 2015; Wallerstein & Duran, 2010; Yardley, Morrison, Bradbury, & Muller, 2015).

Over the past 15 years, our community-engaged research partnership, comprised of lay and academic experts and researchers from academic, government, and nongovernment institutions, including community organizations and businesses, and the community at large, has developed, implemented, and evaluated more than 12 HIV prevention, care, and support interventions for Latinos/as; gay, bisexual, and other men who have sex with men (MSM); and transgender persons. Key interventions are presented in Table 1. These interventions have been designed to increase: HIV testing; condom use; access to healthcare services, including medically supervised hormone replacement therapy services among transgender persons; and pre-exposure prophylaxis (PrEP) and antiretroviral therapy (ART) uptake and retention. Generally, we have followed steps of trust building; fostering collaborative co-learning networks with key stakeholders (e.g., community members, organization representatives, and academic researchers); and iteratively developing, pretesting, implementing, and evaluating interventions (Rhodes, Alonzo, Mann, Freeman, et al., 2015; Rhodes, Daniel, et al., 2013; Rhodes, Duck, Alonzo, Daniel, & Aronson, 2013; Rhodes, Duck, Alonzo, Downs, & Aronson, 2013; Rhodes et al., 2006, 2007). We often have created a Grid of Resources for Intervention Development (GRID), which outlines currently existing interventions that focus on a prioritized health outcome (e.g., condom use and HIV testing); deconstructs how intervention activities meet objectives; assists in evaluating whether interventions and activities address community priorities; and initiates the process of thinking creatively and critically about novel intervention strategies, theories, logical model development, messages, and activities (Rhodes et al., 2006, 2007; Rhodes, Kelley, et al., 2012). Based on our experiences, our community-engaged process to develop interventions has evolved and become more refined over time.

Given the gap in the literature of strategies to assist those who are designing health promotion and disease prevention interventions to reduce health disparities, including HIV disparities, we sought to codify and provide a stepwise process for systematic intervention development.

METHODS

We use community-engaged research approaches (e.g., community-based participatory research [CBPR]) to ensure our interventions are informed by the lived experiences of community members, the experiences and expertise of representatives from community organizations, and sound science. It is well established that interventions are more likely to be effective, replicated, and sustained when they are developed through blending the perspectives of diverse stakeholders including community members, those most closely affected by a health issue (e.g., increased HIV infection rates, low adherence to ART, and limited access to health care and PrEP); service providers and practitioners from health departments/clinics, AIDS-service organi-

TABLE 1. Our Community-Engaged Research Partnership’s Developed HIV-Related Interventions

Intervention	Abbreviated main objective/s	Citation
Brothers Leading Healthy Lives	Increase consistent condom use among African American/black college men	Aronson et al., 2013
ChiCAS (Chicas Creando Acceso a la Salud; Girls Creating Access to Health)	Increase use of PrEP and medically supervised hormone therapy among Latina transgender women	Evaluation in process
CyBER/M4M (Cyber-Based Education and Referral/Men for Men)	Increase knowledge of HIV among gay, bisexual, and MSM who use online chat rooms for social and sexual networking	Rhodes, 2004; Rhodes et al., 2007, 2010
CyBER/testing (Cyber-Based Education and Referral/testing)	Increase HIV testing among gay, bisexual, and other MSM and transgender persons who use social media for social and sexual networking	Rhodes, McCoy et al., 2016; Rhodes et al., 2011
HOLA	Increase condom use and HIV testing within naturally existing social networks of Latino gay, bisexual, and other MSM and Latina transgender women	Rhodes, Daniel et al., 2013
HOLA en Grupos	Increase condom use and HIV testing among Latino gay, bisexual, and other MSM and Latina transgender women	Rhodes, Alonzo, Mann, Freeman, et al., 2015; Rhodes et al., 2017
HoMBReS (Hombres Manteniendo Bienestar y Relaciones Saludables; Men Maintaining Well-being and Healthy Relationships)	Increase condom use and HIV testing within naturally existing social networks of Latino men who are members of recreational soccer leagues	Rhodes, Leichter, et al., 2016
HoMBReS-2	Increase condom use and HIV testing among Latino men	Rhodes, McCoy et al., 2011
HoMBReS por un Cambio (Men for Change)	Promote sexual health (including condom use and HIV testing) and social justice by mobilizing, organizing, and harnessing social networks of Latino men who are members of recreational soccer leagues	Rhodes, Leichter, et al., 2016
MAPT (Mobile Apps to Promote Testing)	Increase HIV testing through GPS-based mobile applications (e.g., A4A/Radar, Grindr, Jack’d, and SCRUFF) among gay, bisexual, and other MSM and transgender persons	Jenkins Hall et al., 2017; Sun, Stowers, Miller, Bachmann, & Rhodes, 2015
MuJEReS (Mujeres Juntas Estableciendo Relaciones Saludables; Women United Establishing Healthy Relationships)	Promote sexual health through naturally existing social networks of Latina women	Rhodes, Kelley, et al., 2012
weCare	Increase HIV care engagement and reduce viral load of young racially/ethnically diverse gay, bisexual, and other MSM and transgender persons living with HIV by harnessing social media (including Facebook, texting, and GPS-based mobile applications [apps])	Prina, 2017; Tanner et al., 2016

zations, and other community organizations who have broad experiences based in service delivery; and academic researchers with expertise in science and theory and ready access to the scientific literature (Viswanathan et al., 2004; Wallerstein & Duran, 2010; Wallerstein et al., 2008).

To develop the process, we abstracted data from existing project documentation including proposal documents, intervention logic models, research team and meet-

TABLE 2. ENGAGED for CHANGE: A Multistep Approach to Intervention Development

Step	Objective
E 1. Expand the partnership	Ensure that necessary key partners and/or critical perspectives are not absent from the partnership
N 2. iNtervention team established	Assign responsibility to a subgroup representing the partnership and its diversity that will push the intervention development process forward
G 3. Gather existing literature and data	Build on what is already known in terms of epidemiologic data, existing local, regional, national, and global data, etc.
A 4. Assess community needs, priorities, and assets	Ensure that community needs, priorities, and assets are blended with existing data
G 5. Generate and refine intervention priorities	Begin the process of focusing intervention goals and objectives are based on community needs, priorities, and assets
E 6. Evaluate and incorporate appropriate theory	Apply theory when appropriate; ensure the intervention is informed by theory
D 7. Design an intervention conceptual or logic model	Describe the logic of the intervention (what is expected to happen)
for	
C 8. Create objectives, activities, and materials	Develop and refine intervention objectives, activities, and materials, including those used in evaluation
H 9. Hone and pretest all activities and materials	Ensure activities and materials make sense for those for whom they are designed
A 10. Administer intervention pilot	Ensure intervention components fit together coherently
N 11. Note process of implementation during the pilot	Document challenges, problems, weaknesses, and successes identified throughout the pilot
G 12. Gather feedback and preliminary outcomes data from those who conducted and participated in the pilot	Include all perspectives in the intervention editing step and analyze collected data
E 13. Edit the intervention based on feedback and findings	Refine the intervention based on lessons learned from the pilot

ing notes, and other materials (e.g., summaries of interventions, progress reports, conference presentations, and papers; Rhodes, 2004; Rhodes, Alonzo, Mann, Freeman, et al., 2015; Rhodes, Daniel, et al., 2013; Rhodes, Duck, Alonzo, Daniel, et al., 2013; Rhodes et al., 2006, 2007, 2011; Rhodes, Kelley, et al., 2012; Rhodes, Leichter, Sun, & Bloom, 2016; Tanner et al., 2016). Partnership members examined these documents and used an iterative approach with review, discussion, and re-review of the steps. This analysis continued until the steps were identified and described.

RESULTS: INTERVENTION DEVELOPMENT STEPS

From our analysis, a 13-step process emerged, which we called ENGAGED for CHANGE, to guide intervention development using community engagement (Table 2).

1. EXPAND THE PARTNERSHIP

Often research partnerships lack representation of critical community and/or academic partners. Partners may not always have the expertise, connections, or other resources that are needed to move intervention development forward. Thus, the first step in the process involves partnership expansion. Although our initial partner-

ship had some Latino members, during our initial study focusing on Latino men's health, we realized that this representation was limited and we needed to expand participation by increasing representation of Latino men who were involved in local recreational soccer leagues. This expansion of representation was not easy and required an investment of time to identify new partnership members, build trust, and increase understanding of the rationale for community-engaged research.

Networking and building trust to expand a partnership can be complicated (Becker, Israel, Gustat, reyes, & Allen, 2013). These processes are ongoing and must be maintained over time to stay connected with communities as they change and grow and to develop relationships with new or emerging communities. However, after initial groundwork is laid, partnerships can build on these connections and experiences to further expand. In our work with Latinos in North Carolina, some members from the Latino community were initially hesitant to participate in processes they initially did not understand or trust. Some were documented, others were not, but most feared engagement because of high levels of racism and anti-immigration and anti-Latino sentiment within local communities (Rhodes et al., 2006; Rhodes, Mann, et al., 2015). This is also true when working with sexual and gender minorities. Partnering with gay, bisexual, and other MSM and transgender persons requires careful consideration and effort given the intersectionality of identities, stigmas, and resiliencies. However, when members of our partnership moved towards developing and implementing an intervention for Latina transgender women, the process was expedited because we already had a favorable reputation after several years of successful research in partnership with Latinos, including Latina transgender women, and were well networked such that identifying community partners was smoother and quicker than prior efforts.

2. INTERVENTION TEAM ESTABLISHED

The next step in the process is the establishment of an intervention team. The intervention team is a small working group, tasked with overseeing intervention development. The team works collaboratively, provides updates, and brainstorms solutions to challenges faced. This team must have broad and diverse representation from the community-engaged partnership. Its work cannot be done in isolation, and the involvement of all partner types, including community members, organization representatives, and academic researchers, is required.

3. GATHER EXISTING LITERATURE AND DATA

This step focuses on describing community needs, priorities, and assets. Strategies may include community assessments that are regularly conducted by public health departments, hospitals, and local foundations; epidemiologic reports from state and national agencies; data collected and used by community organizations in their service delivery and grant applications; and other sources. Different partnership members may be aware of and have access to different types of literature and data depending on their different roles (e.g., organization representatives and academic researchers), and gathering information from a range of sources ensures a more comprehensive picture.

4. ASSESS COMMUNITY NEEDS, PRIORITIES, AND ASSETS

Because not all needed data may be available, a partnership also may need to collect formative data to examine the needs, priorities, and assets of local communities. For example, in the early 2000s, Latino communities in U.S. Southern states,

often referred to as “new Latino settlement states,” remained isolated and were not well understood (Painter, 2008). Collaborating with community members to identify and understand community needs, priorities, and assets has been and remains critical to our intervention research.

We have used multiple research methodologies to identify community needs, priorities, and assets, including focus groups and in-depth individual interviews. One innovative qualitative methodology that we have used frequently is photovoice. Photovoice enables participants to record and reflect on community strengths and concerns through photographs that they take and group discussion triggered by these photographs. Not only does this method provide images of lived experiences, but it also gives an opportunity for participants and others who may be able to support action to collaboratively identify next steps (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009). We have successfully used photovoice with Latino men (Rhodes, Hergenrather, Griffith, et al., 2009), persons with HIV (Rhodes, Hergenrather, Wilkin, & Jolly, 2008), Latina transgender women (Rhodes, Alonzo, Mann, Sun, et al., 2015), and the Korean immigrant community (Rhodes, Song, Nam, Choi, & Choi, 2015).

Data gaps can also be filled using innovative quantitative methods, such as respondent-driven sampling (RDS), which uses chain-referrals, or initial respondents as “seeds” to yield representative samples and prevalence estimates for populations that may be considered difficult to reach by researchers or other outsiders or for which no sampling frame exists (e.g., undocumented Latinos, Latino MSM, and transgender women; Rhodes, McCoy, et al., 2012; Song et al., 2012).

5. GENERATE AND REFINE INTERVENTION PRIORITIES

Next, the intervention team uses the data that has been gathered to generate intervention priorities and, through an iterative process, seeks feedback from the larger community-engaged research partnership, and refines these priorities. For example, during our photovoice project in partnership with Latina transgender women, we discovered the need for more access to sexual health information and services, a finding that aligns with the existing literature on high rates of HIV among transgender women. However, photovoice participants emphasized that access to transition-related healthcare services, including safe hormone use, was a more urgent priority, particularly given the importance of transition-related services for overall well-being, the risks involved with unsafe hormone use, and barriers to health care such as high rates of being uninsured, limited availability of bilingual and bicultural health services, and the lack of culturally congruent transgender-focused services (Rhodes, Alonzo, Mann, Sun, et al., 2015). Thus, some members of our partnership developed the ChiCAS intervention to focus jointly on sexual health and transition-related health based on these qualitative data and on our enhanced understanding of community needs. We are currently evaluating this intervention using a rigorous intervention/delayed intervention study design.

6. EVALUATE AND INCORPORATE APPROPRIATE THEORY

Discussions of theory (e.g., behavioral, educational, and communication) allow partners to understand processes of change at the level at which they plan to intervene, from a systematic perspective, and identify where and how theory relates to their real-world experiences. Exploring theory and its uses and blending it with the perspectives of community members is critical to making informed decisions about intervention development. For example, through such discussions, we determined

that, two theories aligned with our desired approach to supporting the sexual health of Latino gay, bisexual, and other MSM and Latina transgender women: social cognitive theory (Bandura, 1986) and empowerment education (Freire, 1970, 1973; Wallerstein, 1994). We also determined that using a lay health advisor strategy for implementation was authentic to how these communities interact and would allow us to reach a larger number of Latinos. Thus, our HoMBReS (Rhodes, Hergenrather, Bloom, Leichter, & Montano, 2009) and HOLA (Rhodes, Daniel, et al., 2013) interventions, as examples, were designed to train members of recreational Latino soccer leagues and Latino gay, bisexual, and other MSM communities, as well as Latina transgender communities, respectively, to promote sexual health through their naturally existing social networks (i.e., through their friends). Our approach to training and supporting these lay health advisors was informed by constructs from both theories.

7. DESIGN AN INTERVENTION CONCEPTUAL OR LOGIC MODEL

Designing an intervention conceptual or logic model is critical to visually depict the links among determinants of health (e.g., low rates of condom use or limited access to services such as medically supervised hormone therapy and PrEP services); the intervention strategies designed to address these determinants; and expected immediate, intermediate, and long-term outcomes. Thus, the intervention conceptual or logic model allows partnership members to see the logic in their thinking, discuss assumptions, and blend perspectives, insights, and experiences, with science while keeping an eye on concrete health outcomes (Rhodes, Alonzo, Mann, Freeman, et al., 2015).

Within these discussions, community members may evaluate what might and might not work to reach expected outcomes based on their lived experiences and perspectives on health and risk within the context of their community. Service providers, including representatives from community-based organizations, may provide insights based on their rich experience on the front lines of health promotion, disease prevention, and service provision; and academic researchers may synthesize the literature and provide expertise in health behavior theory. As a result of the team-based approach to conceptual or logic model development, new variables may also be identified for measurement, including outcome, mediating, and moderating variables.

8. CREATE OBJECTIVES AND CRAFT ACTIVITIES AND MATERIALS

In this step, a general outline for the intervention including goals, theoretical underpinnings, objectives, and key messages is developed. Intervention activities and necessary culturally congruent materials are then developed according to this outline. During this step, it is particularly important to refer to the logic model to ensure that the intervention activities and materials link to expected outcomes.

This Step also includes the development of materials that will be needed for the evaluation of the pilot test, including process and outcome evaluations. Evaluation materials may include satisfaction surveys, quantitative assessments for pre- and post-tests, and qualitative instruments, such as in-depth interviews.

9. HONE AND PRETEST ALL ACTIVITIES AND MATERIALS

The next step is to hone and pretest intervention activities and materials with community members outside of the partnership. We have learned that over time, partnership members, even those who represent the community, become more like

others within the partnership (including organization representatives and academic researchers) and may become out of touch with their community-based peers. Thus, it is critical to ensure that community members who may be unfamiliar with both the research and the partnership are involved in the pretesting stage. For example, in our weCare intervention we had initially selected iCare as a potential name to play off of the Apple brand (e.g., iPhone) given that we were designing a social media intervention. We also were hesitant to include words or symbols in our logo that were related to HIV, to be sensitive to the fact that participants may not be comfortable being linked on social media to a page or profile that was explicitly related to HIV. However, young racially/ethnically diverse MSM with HIV wanted to use the intervention name weCare; they prioritized a sense of community and social support over the reference to technology. They also felt that it was important that the intervention logo include a red ribbon, which they explained would send a message about HIV being an important issue that we care about within the gay, bisexual, and MSM and transgender communities to reduce HIV-related stigma, and not necessarily an indication of one's HIV status (Prina, 2017; Tanner et al., 2016).

10. ADMINISTER INTERVENTION PILOT

It is also essential to pilot test the intervention in its entirety to explore activities and materials for attention, comprehension, personal relevance, credibility, and acceptability by those for whom the activities and materials are developed (Bartholomew et al., 2001; National Cancer Institute, 1989; Rhodes et al., 2006, 2007). Questions that we have used during this step include: (1) Do activities and materials motivate and sustain the participants' attention and interest? (2) Do activities and materials perceived as they were intended? (3) Is anything offensive or improper in them? and (4) Do participants recognize and identify with the activities and materials (Rhodes et al., 2006, 2007; Rhodes, Kelley, et al., 2012)? Results of this step are used in Step 13 (editing of intervention).

11. NOTE PROCESS OF IMPLEMENTATION DURING THE PILOT

It is critical to learn as much as possible from the pilot. Thus, it is recommended that other partnership members observe pilot implementation. These additional members may complete observer's logs to capture details of implementation, including appropriateness of ice breakers and/or intervention activities, interventionists' fidelity to the intervention curricula, and/or participants' engagement in and reactions to specific activities, in a systematic way. These details may identify where the intervention curriculum is vague, unclear, incomplete, or confusing for those who are delivering the intervention. For example, instructions for intervention implementation may need to be refined.

12. GATHER FEEDBACK AND PRELIMINARY OUTCOMES DATA FROM THOSE WHO CONDUCTED AND PARTICIPATED IN THE PILOT

Discussions with those who implemented the pilot are critical to understand what worked well and what did not. This step also includes outcomes data collection and analysis aligned with the study design for the pilot test. This may include pretest/posttest or intervention/delayed intervention designs as we have often used in pilot studies. We have also conducted qualitative interviews with pilot participants to get feedback to improve the intervention delivery. With participants for whom the intervention successfully promoted intended change, we advise conducting interviews that members of our partnership refer to as stories of success, and

with participants for whom the intervention did not promote intended change, we advise conducting interviews that members of our partnership refer to as stories of learning. This process systematically explores the strengths and weaknesses of the intervention during the pilot phase.

13. EDIT THE INTERVENTION BASED ON FEEDBACK AND FINDINGS

Based on the feedback and results from all steps in the pilot, the intervention team edits and revises intervention strategies, messages, activities, materials, data collection procedures, etc. This is an iterative process with the intervention team revisiting previous steps within the ENGAGED for CHANGE process. Editing is critical to ensure that the most promising intervention—based on the community needs, priorities, and assets; and sound science; and building stepwise on formative and new data—is used and evaluated.

DISCUSSION

Based on our community-engaged intervention research experiences, we developed the multistep intervention development process titled, ENGAGED for CHANGE. ENGAGED for CHANGE provides community members, organization representatives, practitioners, and researchers, a step-by-step guide for intervention development. The 13 steps of ENGAGED for CHANGE rely on a shared mission, a foundation of trust, transparency, clear communication, and unflagging commitment to work together to reduce health disparities by partnership members. Moreover, the steps may overlap and progress iteratively. The process ensures that interventions are informed by the lived experiences of community members, the experiences of representatives from community organizations, and sound science. This process also is iterative and long-term with multiple opportunities for the intervention team and partnership members to provide feedback.

There continues to be a profound need to translate knowledge into interventions designed to promote community and population health, and ENGAGED for CHANGE can serve as a guide for intervention development. ENGAGED for CHANGE is intended to be a flexible and versatile process that may be used in diverse contexts. It may be applied to other health issues besides HIV prevention and care and to other communities and populations besides those that our partnership is comprised of and focused on, and derivations of the process may be warranted. Although our partnership is committed to community-engaged research, the steps we outline may be altered, revised, and abbreviated for different research approaches to engagement.

Each step in ENGAGED for CHANGE is complex, and our intervention development research has not been without challenges. Community members face the realities of health disparities and inequities every day and know that something must be done for these communities and populations. The slow pace of securing funding and conducting quality community-engaged research is an ongoing frustration. Furthermore, communities themselves are not infallible; members of community-engaged research partnerships may have strongly held prejudices about one another that require ongoing attention. This highlights the need to attend to these prejudices and create mutual understanding throughout the course of intervention development, implementation, and evaluation.

It is essential that interventions are rigorously evaluated. Though our partnership believes the stepwise approach laid out in ENGAGED for CHANGE increases the likelihood of developing interventions that are efficacious, outcome evaluation to measure the effectiveness of interventions, as well as process evaluation, are critical for further refining interventions and determining whether dissemination is warranted. Intervention outcomes and process findings can inform dissemination and adaptation of those interventions that are found to be effective and help ensure intervention fidelity. Strong collaborations and diverse perspectives among partnership members are important in evaluation; data collection, analysis, and interpretation; and dissemination of findings (Cashman et al., 2008; Schaal et al., 2016).

Our partnership is committed to innovative, systematic, and theory-based community-engaged intervention development and research because this approach maximizes the probability that interventions are based on what community members identify as priorities; is more informed because of the sharing of broad perspectives, insights, and experiences; builds capacity of all partners to solve problems, harness community assets, and conduct meaningful research, which may reduce health disparities overall; and promotes replicability and sustainability of interventions if warranted. We also contend that working in partnership and building on the strengths of communities, organization representatives, and academic researchers is more ethical; health disparities, like HIV, require that we develop interventions that have the highest likelihood of success to ensure the reduction and elimination of disparities over time. We must maximize our potential for change. Though models, frameworks, and processes are limited, ENGAGED for CHANGE provides a clear road map to guide intervention development.

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