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Abstract

Expected and Unexpected Results: Establishment of a New Community Participatory Research Center

Building on existing partnerships to establish a community-based participatory research program is necessary but not sufficient. The National Center for Deaf Health Research (NCDHR) seeks to promote health and prevent disease among Deaf and hard-of-hearing populations. Guided by the original proposal to establish the Center, initial efforts established infrastructure (dedicated personnel and specialty space to facilitate communication), committees (community, research, communication/dissemination, education, evaluation) and partnerships/contracts (educational institutions; health agencies).

After three years, the above processes were established and moving forward on their priorities. Progress was substantial but uneven across mission areas, and important and unexpected issues involving the project's participatory nature arose.

We engaged NCDHR staff, partners and community members through a structured participatory process of issue identification, solution generation and prioritization over two large facilitated meetings. The resulting action plan includes specific steps to expand access to minutes and reports (including American Sign Language versions); improve connections and communications between NCDHR committees and re-examine NCDHR's organization/committee structure. Follow-up meetings will assess progress.

Community participatory research, a valuable public health tool, requires sustained efforts well beyond initial agreements and planning.

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