

A Beginning Framework for Understanding, Developing, and Implementing  
Universal Design Elements in Community-Based Participatory Research (CBPR)  
and Participatory Action Research (PAR) when applied to Bio-Medical and/or  
Genetics Research where there may be Little or No Immediate Benefit

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**BACKGROUND:**

The NIH Partners in Research Initiative has recently funded various models of Community-Based Participatory Research<sup>1</sup> (CBPR), which is related to Participatory Action Research (PAR). CBPR is defined by the Interagency Working Group for Community-based Participatory Research (August 2, 2002) as scientific inquiry conducted in communities and in partnership with researchers. The process of scientific inquiry is such that community members, persons affected by the health condition, disability or issue under study, or other key stakeholders in the community's health have the opportunity participate in and substantially contribute to each phase of the work (conception, design, conduct, analysis, interpretation, conclusions, and communication of results)<sup>1</sup>. It stems from the realization by NIH that, for the nation's investment in scientific discoveries to change the lives of people, it is critical to move into a new research paradigm, which builds public trust in research and scientific endeavors.

At the heart of PAR and Community-Based Participatory Research is the fundamental belief that good research should utilize processes, which focus on the following:

- (1) Targeted inclusion of the full array of beneficiaries of research as potential subjects and to inform components of the research process and
- (2) Effective collaboration between community members and research institutions

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<sup>1</sup> <http://grants.nih.gov/grants/guide/rfa-files/RFA-OD-07-001.html>

Specifically, the Public Trust Initiative seeks to provide the public with:

1. information about how NIH [and other agencies] conduct and support research;
2. opportunities to participate in priority setting;
3. opportunities to participate in research, and;
4. access to, and understanding of, research results.

*[Note: Information was slightly modified to be more generally applicable to this discussion]*

### FOCUS OF THE DISCUSSION GROUP:

PAR and CBPR is especially relevant for the inclusion of research beneficiaries who are traditionally under-represented, such as individuals from diverse cultural and linguistic groups, individuals with disabilities, and/or individuals and their family members with limited education and resources.

Work over the past ten years has provided excellent models for PAR when applied to individuals with disabilities—frequently related to psycho-social or psycho-educational research. These principles/strategies will be examined and applied to research which focuses on bio-medical and/or genetics research which has unique challenges for recruiting subjects as there is frequent little or no immediate benefit. It is argued that these basic principles for working with research subjects and beneficiaries of research are universal in their application.

This work is informed by related literature and work the USC UCEDD has specifically done with PAR and Engineering Research and are currently doing under an NIH Partners in Research Grant (with the USC Center for Genomic and Phenomic Studies of Autism—NIH U24 multi-site collaborative), to diversify their subject pool to include subjects from ethnic groups currently under-represented within the database of the Autism Genetic Resource Exchange (AGRE).