



Disability-focused Community-based Participatory Research: Learnings

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What is Community-Based Participatory Research?

Lewin's action research in the 1940s

...challenged the gap between theory and practice and used a research cycle involving planning, action, and investigating the results of the action to solve practical problems



Emancipatory participatory research that emerged in the 1970s in Latin America, Asia, and Africa

...shift from being objects of study to being part of enquiry.
Research not neutral but committed to with critical consciousness, emancipation and social justice.
Research role challenged



CBPR (1990s onwards)

CBPR Synergy with 2030 Agenda



Approaches to implementation

- **“foster shared responsibility”**
- **“mobilize all available resources”**
- **“commit to multi-stakeholder partnerships that mobilize and share knowledge and expertise”**
- **“be open, inclusive, participatory and transparent”**
- **“support reporting by *all* relevant stakeholders”**
- **“be people-centered, gender sensitive, respectful”**

Features of CBPR



**Level hierarchy
where possible**



**Mutual dialogue &
understanding**



**Shared decision-
making & ownership**



Peer researchers interviewing
teachers in Kenya

Features of CBPR

Members of the community are actively involved in:

- **planning**
- **data collection**
- **analysis**
- **dissemination**



Community research team in Cameroon

Ethical Principles of CBPR



Community members in India

- mutual respect
- personal integrity
- equality and inclusion
- democratic participation
- active learning
- making a difference
- collective action

Aim of CBPR



To increase knowledge and understanding of a given phenomenon



To integrate the knowledge gained with interventions, policy and social change



To improve the quality of life of the community



A child learns in Rajasthan, India

CBPR projects and locations

Completed:

Tanzania: Hear my Voice (social inclusion)

Malawi: Let's grow together (education EY)

Uganda: Youth Economic Empowerment (social inclusion)

Sierra Leone: Education for All (7-16 education)

Ongoing:

Kenya: Pamoja project (education)

Senegal: Education and gender project

Cameroon: Education and gender project

Nigeria: NTD morbidity management (NTD)

Impact on intervention design

Research finding:

Boys and girls with disabilities are suffering from peer bullying and unintentional hurt in schools

Single mothers of boys and girls with disabilities have even greater struggles

Teachers feel ill-equipped to manage the pupil-pupil tensions of inclusion in their classroom

Action:

child-to-child club within the schools which addresses the issue of bullying

Members of the established mother's club now provide tailor-made support

Teacher training provided specific to this issue. Teachers reporting greater confidence in classroom management

Impact on intervention design

Example from Kenya Pamoja project

Research finding #1:	Prior to phase 1 of research	Current stage of project
Greater focus needed on community and school sensitization around disability inclusion (specific examples cited)	Intermittent, unplanned and with long gaps Unstandardised content Community mobilization initially done only by EARC staff with minimal impact	Reliable, consistently planned sensitization interventions conducted twice quarterly Awareness-raising uses standardized content focusing on: <ul style="list-style-type: none">• disability & its causes• types of support available and where to get it• referrals for specialized services Undertaken by the sub-county EARC staff, teachers, religious leaders, local administration and CHVs Takes place in designated centrally positioned schools to ensure maximum attendance



Successes

- Connection between participants and interviewers
 - Peer researchers disseminating their research
 - Meaningfully including peer researchers with physical impairments



Successes

- Sustainable change locally
 - Training design
 - Relatively low cost
- Informs policy and programmes

Authentic relating principles

Weaving AR into CBPR

- Welcome everything
- Assume nothing
- Reveal your experience
- Own your experience
- Honour self and other



Tensions and Dilemmas

- Reporting back findings in time to influence the decision-making processes
- Ensuring CBPR ethical principles are fundamental to the study can be in tension with cultural norms
- Power differences can remain substantial - not always clear what working towards sharing power more equally looks like in practice

Tensions and Dilemmas

- Peer researchers cannot be as included in planning to extent CBPR methodology requires
- Still learning how best to include peer researchers in data analysis
- Slow to include those with speech difficulties or intellectual difficulties as part of a community research team

Evolving CBPR design

- Greater inclusion in recruitment process
- Inspiring and inclusive data collection tools
- Support to embody CBPR ethical principles
- Differentiated analysis
- Two-stage findings



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Thank you

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