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)

Sources: Lewin (1948/1997), Freire (1970)
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”

(paragraphs 36, 39, 74 and goal 17)
Features of CBPR

- Level hierarchy where possible
- Mutual dialogue & understanding
- Shared decision-making & ownership

Peer researchers interviewing teachers in Kenya

(Greenwood et al, 2016; Levine-Rasky 2015; Kemmis & McTaggart 2005)
Features of CBPR

Members of the community are actively involved in:

- planning
- data collection
- analysis
- dissemination

Community research team in Cameroon

(Greenwood et al, 2016; Levine-Rasky 2015; Kemmis & McTaggart 2005)
Ethical Principles of CBPR

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

Community members in India

(CSJCA & NCCPE 2012)
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

(Greenwood et al, 2016; Levine-Rasky 2015; Kemmis & McTaggart 2005)
# 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

<table>
<thead>
<tr>
<th>Research finding #1:</th>
<th>Prior to phase 1 of research</th>
<th>Current stage of project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater focus needed on community and school sensitization around disability inclusion (specific examples cited)</td>
<td>Intermittent, unplanned and with long gaps</td>
<td>Reliable, consistently planned sensitization interventions conducted twice quarterly</td>
</tr>
<tr>
<td></td>
<td>Unstandardised content</td>
<td>Awareness-raising uses standardized content focusing on:</td>
</tr>
<tr>
<td></td>
<td>Community mobilization initially done only by EARC staff with minimal impact</td>
<td>• disability &amp; its causes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• types of support available and where to get it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• referrals for specialized services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Undertaken by the sub-county EARC staff, teachers, religious leaders, local administration and CHVs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Takes place in designated centrally positioned schools to ensure maximum attendance</td>
</tr>
</tbody>
</table>
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
References


Thank you

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Disability-focused Community-Based Participatory Research: How is methodological learning shaping design and approach?