The capacity of community-based participatory research in relation to disability and the SDGs

Margo Greenwood[a*]

[a]*Sightsavers. Corresponding Author- Email: mgreenwood@sightsavers.org*

The 2030 Agenda pledges to foster shared responsibility, recognizes all as crucial enablers of sustainable development, and calls for the mobilization of all available resources. It also commits to multi-stakeholder partnerships and pledges to be open, inclusive, participatory and transparent in its follow-up and review. Community-based participatory research (CBPR) equitably involves community members, organizational representatives and researchers, enabling them to share power and resources through drawing on the unique strengths that each partner brings. It aims to integrate any increased knowledge and understanding into action, policy and social change to improve the health and quality of life of community members. CBPR involves recruiting community or peer researchers, involving them in planning and offering them training to undertake interviews and observations in their context. They are also part of the analysis and dissemination process, and continue to work with local partners on advocacy plans and events after projects and research have finished. People with disabilities are actively part of the research process throughout. Drawing on relevant literature and current CBPR disability research in East and West Africa, this paper puts forward CBPR as a methodology that can enable community members to identify key barriers to achieving the SDGs, and inform how policy and programmes can be altered to best meet the needs of people with disabilities. It demonstrates CBPR in practice and discusses the successes and complexities of implementing this approach in relation to the SDGs. The paper also highlights findings such as the high level of support needed for community research teams as they collect data and formally disseminate it, the honest raw data from peer to peer interaction, a deep level of local ownership at advocacy level, emerging issues surrounding meaningfully involving community researchers in analysis, and power differentials. A key conclusion is that to join partners with diverse expertise requires much planning, diplomacy, and critical, reflexive thought, while emphasising the necessity of generating local ownership of findings and the translation of knowledge into a catalyst for disability-related policy change.

Keywords: SDGs; Community-based participatory research; education; social inclusion

Introduction

Inclusion of disability in the SDGs creates greater possibilities for people with disabilities to feel the impact of development progress. The 2030 Agenda for Sustainable Development (2015: 4) states that no one must be left behind and pledges to reach those furthest behind first. The SDGs and targets within the Agenda include seven targets that explicitly refer to people with disabilities and include disability-related indicators. An additional six SDG targets refer to people in vulnerable situations, which include people with disabilities. More broadly, two other targets address discrimination – a key cause of unequal access. Several other targets are universal ones, which must also be achieved for people with disabilities. Alongside this, it underlines that the Goals and targets are integrated and indivisible (55). Therefore, it is important to recognise that people with disabilities need to be considered in the whole Agenda and not just targets that specifically mention them. Research is needed to explore how best to achieve the SDGs in relation to disability, including gendered disability. Pressure needs to be maintained on governments to include people with disabilities in their development plans, especially when inclusion is challenging or costly. Importantly, people with disabilities need to be vital actors in the process of both. Their voices, embedded in their own journey and identifying their own terms, bring contextual clarity, and demonstrate to governments what is at stake. Their voices also limit the risk of people with disabilities being seen as homogenous. Certainly, 'a lack of responsiveness to what is needed on a local basis arises from the disregard for local identities and the diversities that lie therein' (Cutajar & Adjoe, 2017: 510). As people with disabilities research what is needed to implement the SDGs, raise their concerns with their own governments, and work in partnership to deliver progress, the inclusion of disability in the SDGs provides a powerful justification tool for inclusive change.

This paper puts forward community-based participatory research (CBPR) as a methodology that can enable community members, including people with disabilities, to identify key barriers to achieving the SDGs and inform how policy and programmes can be altered to best meet the needs of people with disabilities across the whole Agenda. At a practical level, CBPR involves recruiting community or peer researchers, involving them in planning, and offering them training to undertake interviews and observations in their context. They are also part of the analysis and dissemination process, and continue to work with local partners on advocacy plans and events after projects and research end (Greenwood et al., 2016). CBPR helps to build the picture of disparities in education, health, finance and beyond, and enables the definition of equal access to all levels by those experiencing it in relation to disability. It embodies the 2030 Agenda's pledge to leave no one behind and reach the furthest behind first. A CBPR approach is also in keeping with the "Nothing about us without us" philosophy of the Disability movement (Charlton, 2000), which expresses that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected.

Within its argument, this paper aims to consider related literature and describe and critique the methodology and practical process, drawing on organisational-specific research. A reflections section describes the successes, tensions and dilemmas of the methodology including its contribution to defining SDG progress and barriers, with a focus on social inclusion and education. Conclusions will be drawn on the realistic use of the methodology in relation to disability and helping to achieve the SDGs. An aim of this paper is to connect with others interested in and employing this methodology in the field of disability.

Literature Review

The historical roots of CBPR stem from Lewin's action research in the 1940s (Wallerstein & Duran, 2008) that challenged the gap between theory and practice adopting a research cycle involving planning, action, and investigation of the results of the action to solve practical problems (see Lewin, 1948/1997). This problem-solving utilitarian approach has been adapted by humanistic psychology research to include a cooperative enquiry strand that promotes human agency and insists on researcher and community member reciprocity (ibid, 2008). CBPR also stems from a second tradition of emancipatory participatory research that emerged in the 1970s in Latin America, Asia, and Africa (ibid, 2008). Reflected in the work of Freire (1970), communities shifted from being objects of a study to being part of the enquiry. Research was not neutral but was committed to critical consciousness, emancipation, and social justice while challenging the research role. Freire showed that as people engage in dialogue about their communities and beyond, their own thought patterns and beliefs about their world change, their relationships strengthen, and they build their capacity to reflect on their own values and make new choices (Wallerstein & Duran, 2008). Drawing from both traditions, this paper defines CBPR as:

> ...about knowledge creation and the value of practical and critical emancipatory reason for understanding power dynamics, for recognizing the interconnections between the personal and the social and between life worlds and system worlds, and for identifying the barriers to and facilitators of human actions that move toward the goal of social change (Wallerstein and Duran, 2008:40).

These combined roots of CBPR history provide an approach that resonates with the problem-solving and emancipatory nature of the (2015) 2030 Agenda, and specifically the SDGs and their targets. There is a capacity for synergy in the process of engaging in CBPR to research ways to implement the SDGs and in tracking SDG progress. For example, the Agenda pledges to foster shared responsibility, and recognizes that all cultures and civilizations can contribute to and are crucial enablers of sustainable development (para 36). It calls for the mobilization of all available resources (para 39) and Goal 17.16 commits to multi-stakeholder

partnerships that mobilize and share knowledge and expertise. In terms of follow-up and review, it pledges to be open, inclusive, participatory and transparent for all people and will support reporting by all relevant stakeholders (74d). Furthermore, follow-up and review will be people-centred, gender sensitive, respect human rights and have a particular focus on the poorest, most vulnerable and those furthest behind (74e). This alignment between CBPR and the SDGs holds much potential. However, it also requires a commitment to overcome complex tensions and dilemmas that arise out of such a methodology, outlined in the reflections section below.

On a practical level, CBPR involves respectful collaboration with the community. Its non-hierarchical approach, incorporating mutual dialogue and shared decision-making, actively involves members of the community in planning, data collection, analysis and dissemination (Greenwood et al., 2016). It is an orientation to research that recognises the unique strengths that each person brings, whether a school pupil with a disability, an organisational representative or a professional researcher. CBPR seeks to break down social injustice and the structural constraints that produce inequities of power (Levine-Rasky, 2015). It demands an awareness of positionality with vigilance towards one's own power (Pain, Kindon, & Kesby, 2007). The approach increases knowledge and understanding of the situation being studied together, constructs meaning together and integrates this with interventions and policy change to improve the quality of life for those of focus in the community (Greenwood et al., 2016). From the 1990s, CBPR emerged as a research paradigm that integrates education and social action to improve health and reduce health disparities. Since 2015, several organisations have explored shifting the focus of CBPR beyond health to broader social inclusion and education outcomes, as a result of engaging with how best to implement the SDGs.

Ethical principles are recommended for CBPR by the Centre for Social Justice and Community Action and National Co-ordinating Centre for Public Engagement (CSJCA and NCCPE, 2012 cited in Greenwood et al., 2016):

- Mutual respect– for example, being prepared to listen to the voices of others, accepting that there are diverse perspectives;
- Equality and inclusion– for example, seeking actively to include people whose voices are often ignored, challenging discriminatory attitudes and behaviours and ensuring information, venues and formats for meetings are accessible;
- Democratic participation– for example, acknowledging and discussing differences in the status and power of research participants, working towards sharing power more equally, using language everyone can understand;
- Active learning– for example, ensuring time to identify and reflect on learning and sharing responsibility for interpreting the research findings and their implications for practice;

- Making a difference– for example, debating what counts as positive change and building it in as a goal;
- Collective action– for example, agreed visions and goals that meet partners' differing needs for the research and for how to share knowledge and power more equitably;
- Personal integrity– for example, accurate and honest analysis and reporting of research, being open to challenge and change and prepared to work with conflict.

In addition to aligning with the aims of the 2030 Agenda, the principles of CBPR fit well with critical disability research, which emphasises that 'the poorest, including disabled people, continue to survive on their own accord, using their own means, and it is these means and strengths that we need to build upon and ensure that we do not trample upon or destroy discursively or materially' (Grech, 2016:17).

There is a clear call within disability literature for an approach such as CBPR. Prioritising the voices of people with disabilities, their families and communities is a 'critical starting point, even when these voices may go against our own subjectivities, definitions and approaches to disability and development' (Grech, 2016:17). People with disabilities must own and define the process on their own terms (Grech, 2016; Meekosha and Soldatic, 2011), and the process of engagement has to be interactive and bi-directional (Rioux, 2016). These elements are at the heart of CBPR. Yet, as expressed, undertaking CBPR with people with disabilities is innovative and there are few models to build on for the global South context (though acknowledgement is made of similar disability research in high income countries such as in Walmsley, 2004; Nind & Seale, 2009; Stalker, 1998). Grech (2016:12) highlights how the voices of people with disabilities in poverty, especially in rural areas are 'seldom heard and contemplated, too often drowned in the perspectives of so-called experts and professionals'. In addition, Brolan (2016: 22) argues that disability advocates must press for implementation of the SDGs to not be exclusively focused on the quantitative by reducing disability-inclusive development to 'the numbers', an approach that submits to an 'all-consuming focus by government on quantitative measurement' which is 'not only morally unacceptable; it is unlawful pursuant the terms of the CRPD.' In measuring SDG achievement for people with disabilities, the voices and the experiences of SDG development on people with disabilities and their supporters must be captured.

We know that 'gender stereotypes interact with disability stereotypes to constitute a deep matrix of gendered disability in every culture' (Meekoshka, 2004:9). Yet, women with disabilities from the global North and South could set 'radical political priorities', starting with hearing 'the voices of the poorest and the disinherited among them' (Price and Golay, 2016: 317). Acknowledging this, Foran's (2017) review on gender and disability highlights how little research and programmes address the experiences of women and girls with disabilities as distinct from those of men and boys with disabilities and relative to females

and males without a disability. This has inspired a CBPR gendered disability study outlined below (see Greenwood & Foran, 2017). Clark and Sawyer (2014:6) also emphasize that 'much of the analysis of education for children with disabilities lacks a gender perspective while much of the discussion of gender equality in education overlooks the added problems faced by children with disabilities'. In relation to ensuring inclusive and quality education for all (SDG 4), the term inclusive education is representative of education for all, but we have yet to define what that term means for those with disabilities in a global context (McCall, 2017).

There is not the scope in this paper to explore all crossovers with CBPR in relation to implementing the SDGs. However, it is worth acknowledging that there are links between CBPR and Communities of practice (Lave, 1991; Wenger, 1998), understood as groups of people who share a concern or passion for something they do and learn to do it better as they interact regularly. Communities of practice enable a collective responsibility for managing knowledge, create a direct link between learning and performance, and address the aspects of knowledge creation and sharing. Connections are formed across organizational and geographic boundaries. These features are also a key part of CBPR, instead woven into a systematic research process. CBPR also resonates with indigenous research methodology – place-based methods of collecting and disseminating data, with awareness of the world view and cultural values of the researcher and the community where the research is taking place. The methodology flows from indigenous knowledge, and information is gleaned through relationship, including with the story itself and how it is interpreted by whoever is present. In certain models, the research project and data is taken out of the hands of the researcher, who becomes an observer (Kovach, 2009; Smith, 2012; Wilson, 2008). Its methodology links to the emancipatory nature of CBPR, as indigenous research recognizes the colonizing role of research, education, and religion in its communities. Wallerstein & Duran (2008:33) highlight how discourses have been used by economic and government bodies to 'deauthorize' traditional ways of knowing in order to control native populations and places. Indigenous researchers, by comparison, take the view that 'one of the canons of good research is that it should never hurt the people studied'.

In seeking-out existing CBPR research, the author found only one article on CBPR in relation to disability and the SDGs. This demonstrates a significant gap in literature and known practice on this intersection, though it is important to acknowledge there has been little time for literature to accumulate since the launch of the SDGs. Greenwood et al. (2016) provide evidence on the specific nature and experiences of people with disabilities and older people from their own perspectives in rural and urban settings in Tanzania. A CBPR approach was used, where peer researchers and research partners collected and analysed interviews with people with disabilities and older people, leading to policy and advocacy recommendations and early stage plans. These were explicitly linked to the SDGs in the main report (Mrisho et al., 2016). One article on CBPR and disability in the global South was found, without

reference to the SDGs. McDonald & Stack (2016) conducted a qualitative study to explore the experiences of scientists and community members in a multi-year CBPR project with people with developmental disabilities. The paper reports difficulties adhering fully to CBPR principles, challenges in identifying and maintaining accommodations for participants, missed meetings due to transport challenges, and times of uncertainty with roles and responsibilities. However it concludes that CBPR is possible and fruitful, and can serve as an effective model for the full inclusion of people with developmental disabilities in science and society.

The following section on practical processes draws from the first year of a four-year CBPR study in Kenya (Greenwood, Le Fenu & Owuor-Oyugi, in development), funded by Sightsavers, which focuses on what education inclusion means for children, parents and teachers in five pilot schools in Homa Bay. It also draws on the first year of an ESRC-DFID funded early years education project in Malawi, with community researchers capturing stories of parents and teachers and shaping interventions from the findings. New research with a focus on gendered disability has just started in Cameroon and Senegal (funded by Irish Aid), and in Sierra Leone, funded by the EU. Here, much has been learnt from the early stages of working with community members, peer researcher training and planning of interviews and observations. The West Africa projects have an explicit focus on Goal 4 (Ensure inclusive and equitable quality education and promote lifelong learning opportunity), specifically SDG 4.1 - Ensure that by 2030 all girls and boys complete free, equitable and quality primary and secondary education; and SDG 4.5 which commits to eliminating gender disparities in education and ensure equal access to all levels of education and vocational training for vulnerable people, including people with disabilities, indigenous peoples and children in vulnerable situations by 2030.

Considering CBPR practical processes

The research question being asked determines the methodology. CBPR research relates to the collection and analysis of mainly qualitative data, which can also be part of wider mixed methods research. Some basic quantitative data can also be gathered as part of the approach. The following are examples of questions that have led to CBPR as a chosen approach. Getting to the stage of deciding on the research question ideally has already involved community participation via partners:

- How are boys and girls with disabilities, their parents and their teachers experiencing school inclusion, and what do they suggest as key goals of the upcoming intervention?

This is a question being asked at stage 1 within the Pamoja education project in Kenya, led by Sightsavers, with operational research built in to each stage of the four year project. The

project has a primary objective that links to target SDG 4a: build and upgrade education facilities that are child, disability and gender sensitive and provide safe, nonviolent, inclusive and effective learning environments for all. A total of ten teachers, governors and parents of children with disabilities have become community researchers (only one with a disability).

- What are the current approaches for promoting inclusive early childhood development education (ECDE)? Where do the intervention inclusion strategies and approaches lead to in terms of developmental progress and learning outcomes for children?

This question is being asked in a DFID-ESRC mixed-methods research project [i]which also contains a trial. The SDGs are not explicitly mentioned in the proposal, but the primary objective links to SDG 4.

- How do young people with disabilities perceive their development of skills and chances of sustainable livelihood? What are the families' capacity-strengthening experiences?

The above research question is from a Ugandan research project which is bridging the end of a project[ii] on economic inclusion and the beginning of an extension project. The research is capturing perceptions of skill development, sense of future and capacity-strengthening in order to help shape the extension project. The programmatic projects are addressing SDG 10.2 (with a focus on economic inclusion, disability and youth): by 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status. The research contributes to this by capturing the perceptions of young people with disabilities and their families and ensuring that they help shape action and change going forward. All peer researchers are young people with disabilities who have participated in the project. Obviously, the research only contributes to one part of SDG 10.2. It is also limited to the capacities of the intervention projects and their budgets. However, the CBPR methodology and approaches offer opportunities for empowerment through the peer researcher role. This, in turn, could affect the outcomes of the project itself, which raises questions about the potential impact of CBPR research on the context it is studying, and how influential operational research should be.

- How do children with disabilities, teachers, carers and community members experience or perceive disability in primary schools in Cameroon/Senegal/Sierra Leone; and what are the implications of these perceptions on the participation and quality of learning of boys and girls with disabilities?

This question is a part of operational research within education and gender projects in West Africa, funded by Irish Aid or the EU. The projects have explicit references to SDG goal 4 and goal 5: Achieve gender equality and empower all women and girls. These are the first

research projects with plans to include older children with disabilities as part of the research process in their schools, though this process, including more complex ethical permissions and training, has yet to start. A main concern of children keeping confidentiality is still in discussion.

The research questions not only strengthen specific projects, but also help to understand priorities and challenges for people with disabilities across the whole 2030 Agenda, and better understand the intersectionality within it: they help to tell a whole story whilst linking to specific Goals.

After gaining ethical permissions from a local university, the next steps are:

1. Researchers or country offices work with local partners (and schools/employers) to recruit peer/community researchers who also need to give informed consent to participate
2. Peer/community researchers undertake training in methodology/ethics/interview and observation techniques, led by a researcher experienced in participatory research
3. Peer/community researchers collect data in their context, supported by project partners, ensuring that ethical consent from participants is collected
4. Inductive analysis is usually undertaken by university partners and shared with peer/community researchers.
5. Deductive analysis is undertaken in group workshop with peer/community researchers, usually led by university partners.
6. Findings are written up by partners and shared with peer/community researchers for input.
7. Peer/community researchers and partners plan dissemination and advocacy work going forward.
8. Peer/community researchers and local partners are a key part of dissemination and future advocacy work stemming from findings.

In these contexts, a peer/community researcher is someone who lives in the local area where the research or project is taking place, cares about the research topic, and is not a professional researcher. A small group of peer/community researchers participate alongside a professional researcher, interviewing community members and observing professional situations, enriching the research with their unique contribution. Where a community researcher is interviewing their peers, such as other teachers or other youth with disabilities undertaking the same training course, the term 'peer researcher' is used. Peer or community researchers with disabilities are actively encouraged to participate. They contribute either within independent research projects that are linked to inclusion programmatic projects, or within research that is in-built into a programmatic project.

It is those already discussing disability inclusion and rights in their context who often become peer researchers. Generally, schools or local NGOs are asked to suggest individuals who might be keen to become involved as a researcher. Some individuals are an obvious choice, and the opportunity offers group support for their energies. Peer or community researchers have not been paid a wage for their contribution in the examples of research described. Beyond expenses, investment has been made in training and they often benefit from specific interventions stemming from the research they are involved in. However, as CBPR is a methodology that seeks to engage with power differences in research, it is possible that a wage for peer researchers should be considered in order to counter hierarchy.

A training format for peer and community researchers has been developed over time, which is adapted according to the size and characteristics of the group, and the amount of local research support available at the country office. For example, in Tanzania for the *Hear My Voice* research, the 26 peer researchers were trained over five days, due to the large number of peer researchers with disabilities. Time was needed to make sure that all elements of the training were fully accessible and not rushed. This was also the case for 24 young people with disabilities in Uganda who are peer researchers in the economic empowerment research, where peer researchers also needed this amount of time to feel confident in the role. However, in Kenya, Malawi and West Africa, fewer peer researchers with disabilities were recruited and project managers were able to offer significant support afterwards, so training took place over only two or three days. Currently, the draft training format is not available to the wider research community, which will need to be addressed.

The peer researcher training focuses on understanding, skills and confidence. Although there are notes on the training for the group, training is designed to include those who are not literate or are visually impaired: content begins with the methodology being verbally explained but also demonstrated through practical warm-up exercises. These exercises are designed to be inclusive, and can be adapted further for physical impairments, such as role play characters being carefully chosen according to range of movement. Programmatic project details are made more familiar if the research is within an education or social inclusion project, and in either research context there is clarification on what the research needs to find out. Ethical considerations are discussed in depth, including CBPR ethical principles, informed consent, the strict nature of confidentiality and the few circumstances under which to break it – such as in situations of reported sexual abuse. A key part of the training at this stage is the approach to interviewing: gathering rich data with respect. A wealthy resource for doing so has come from the authentic relating movement – a practice to access more depth and connection with others – which has principles that can be applied successfully to qualitative research, especially during open and semi-open interviews. In particular, five principles (Wilkinson & Thompson, 2016) from an authentic relating practice called 'Circling' (Sengstock, 1995) are showing clear signs of helping peer and community researchers to clarify and deepen the thought process with respect during training sessions

and interviews. These are:

- Be committed through connection: choose to stay in the situation exactly how it is, rather than appease, modify, or change the subject to avoid discomfort.
- Trust your experience: let go of the notion of 'should' and trust that what you are feeling is what you are supposed to be feeling. Express authentically and it will build connection.
- Be with the other person in their world: be curious of the individual's in-the-moment experience without assumptions of knowing what it is actually like.
- Own your experience: take responsibility for your emotions and hold others responsible for theirs. Withholding can deny both parties the opportunity of genuine connection, but share in a way that is respectful and considerate.
- Stay at the level of sensation: check in with your body and use it as a cue to know how a situation is going and how you feel about it. By doing this, it is easier to remain connected to your emotions.

Specific exercises and role-play activities that link to these principles are explored for an interview or focus group situation. During *Hear My Voice*, the research project in Tanzania, very challenging experiences were shared with peer researchers, such as attempts on the lives of people with albinism, and domestic violence by partners and their family on individuals with disabilities. This demonstrates the intersectionality of issues expressed in the 2030 Agenda, with multiple issues coming into play within the stories. When difficult stories emerge, it might be tempting for peer researchers to break the connection because it feels difficult to hear, especially if avoidance has become a habitual impulse, so this is worked through in the training. By having a fundamental trust in our own and others' experiences, it avoids being fixed or attached to anything being 'right' or 'wrong' in an interview or focus group setting. Alongside this, learning to bring a curiosity which assumes nothing and allows for deeper understanding can lead to a meaningful interview, observations and rich data. Peer researchers practised being curious about an individual's in-the-moment experience without assuming they knew what it was actually like. Incorporating Circling principles into the CBPR process explicitly builds relationship. It is a subtle and strong foundation for Goal 17.6 to be open, inclusive, participatory and transparent.

When collecting data, the aim has been to ask peer researchers to be involved but not overloaded. In Tanzania for *Hear My Voice*, 26 peer researchers undertook 106 individual interviews (for details of this study see Greenwood et al., 2016). In Kenya, for the *Pamoja* project, ten peer researchers led focus groups with children with disabilities, parents of children with disabilities and class teachers in five schools, with two peer researchers based in each school. In Malawi, for *Let's Grow Together*, community researchers worked in pairs to lead focus groups with care givers and parents of children with disabilities in ten community-based child centres. The aim has also been for data collection to be local in order

to avoid excessive travel. This may risk issues of confidentiality if interviewees are known to peer researchers, hence clear training on the strict nature of confidentiality and the dangers of breaking it. Peer researchers have seemed to feel more confident working in pairs in the various settings, especially in relation to making sure the voice recorder is on and capturing each voice. Often, more parents of children with disabilities than anticipated have come to the school to be interviewed, so these interviews have been led as focus groups. Observations led by peer and community researchers have included the Harvard See-Think-Wonder thinking routine (Project Zero, 2010). Its observation framework promotes awareness that what is seen is not the same as one's thoughts, opinions and questions about it, avoiding some unconscious merging of these. This can also create opportunity to discuss unconscious bias in data collection and analysis, based on peer researchers' experiences.

Data analysis within CBPR needs to ensure that a systematic coded analysis of the data is undertaken and that peer and community researchers are part of the analysis process. Different approaches have been taken in the few CBPR research examples available. The most recent and successful one seems to be when the inductive coding is undertaken on approximately two thirds of the data by a researcher, followed by the peer researchers taking part in analysis workshops and coding the remaining data deductively using the framework emerging from the first set of coding. This way, the coding workshop analysis is supported by a set of codes with which the peer researchers can orientate themselves, but they can also identify new codes from the remaining data when evidence does not fit within existing codes. This structure also works well for people with visual and hearing impairment, as the coding framework is a verbal and visual anchor for the activities.

In the small sample of CBPR research projects thus far, the dissemination stage has involved peer researchers reporting back at a local and national level. Professional researchers have taken responsibility for writing reports and journal articles, and have included country office directors as co-authors where possible (for example, Greenwood et al., 2016). It has been important that those involved in policy and advocacy have been involved from the start, rather than once the findings are ready to disseminate. This enables the context and complexity of the work to be discussed from a policy and advocacy perspective throughout the life of the project. One example of embracing this was for the policy and advocacy team at Sightsavers to be part of group data analysis during the research in Tanzania, *Hear My Voice*. This enabled them to track the trail of evidence leading to their focus on SDG goal 10 to reduce inequality and empower and promote social, economic and political inclusion in that context. Peer researchers provide a joined up approach at local level. Within the Tanzania research, peer researchers have participated in village meetings, planned to provide sexual education to communities, and actively engaged with local authorities to implement the National Disability Policy of 2004 and provide better support and provision of services to families of people with disabilities (Greenwood et al., 2016).

The process of involving the community in data collection, analysis and dissemination, through CBPR, offers an effective approach to monitoring the SDGs. The Secretary General's synthesis report (2014: para 146) calls for "a culture of shared responsibility" with "shared rules and evidence, collective action" and "broad, multi-stakeholder participation". In particular, the required regional and thematic monitoring – such as in education – can benefit from a CBPR approach. Regional monitoring helps to foster regional collaboration and coherence in strategies. Embedding SDG monitoring in a CBPR approach could create a powerful and accountable path to regional and thematic implementation of the SDGs. As already discussed, a methodology and practical outworking so sensitive to context and complexity brings with it tensions and dilemmas that need addressing as part of that path, as outlined in the following section.

Some reflections

This section is divided into key successes, value tensions and dilemmas (with acknowledgement that the delineations are artificial, in a constant state of flux and overlap), with discussion throughout.

Successes

Some parts of the CBPR processes work better than others, as is common with all approaches. These have been the key positive findings so far within education and social inclusion research:

- There have been community members waiting for an opportunity such as this. When they find their way onto the research team, they can make a considerable contribution to the research process: a primary school teacher encouraged a large number of parents of children with disabilities to come and share their experiences- these had never been engaged before; a person with albinism patiently waited for others with albinism to feel safe enough to meet during an election; a parent is supporting other peer researchers and building a sense of a research community. Such voices help to make SDG implementation sustainable locally. Women have been nearly evenly represented in peer research teams.
- Drama, games, role play and exploring deep feelings and thoughts outside in the shade in the peer researcher training, has created an uplifting and bonding experience that seems to help them remember the learning points whilst undertaking the interviews and observations (taken from peer researcher feedback documentation).
- The cost of undertaking CBPR has so far been relatively low. Training venues can be hired cheaply from disability action groups, interviews are often held in schools at no cost, with teachers and children already there, and transport costs for parents are

reasonable. Data collection is done voluntarily covering costs and dissemination is often local with community members helping to set it up. Main costs can be on transcription, translation and ethics permission fees.

- Transcripts from *Hear My Voice*, Tanzania and *Pamoja* in Kenya have shown key moments when a connection between participants and interviewers has enabled the interviewee(s) to open up and express their experiences more deeply than they first offered, or to really commit to exploring idea generation of ways forward (with no examples yet of privacy concerns about the researchers being members of the community). This indicates that the authentic relating principles (Wilkinson & Thompson, 2016) woven into the training are having an impact.

- A peer researcher disseminating his/her research at events has been powerful. For example, during *Hear My Voice* at a large policy launch in Dar es Salaam, policy makers and national press heard them speak and commented on the impact of self-representation. This can continue beyond the life of the project.

- It has been fairly straightforward to meaningfully include peer researchers with physical impairments into the research process. Peer researchers with visual or hearing or a number of physical impairments, with careful planning and budgeting, have been fully engaged in the training, data collection, analysis and dissemination. There have been oversights and miscommunications, but as partners in the process, peer researchers with disabilities have helped to shape each stage of the process to make it more accessible. What has not worked has been changed together.

- At a micro-level, CBPR has begun to inform how policy and programmes can be altered to best meet the needs of people with disabilities, build the picture of disparities in education, highlight the difficulties for people with disabilities in pursuit of employment, and show how people experience disability day to day, individually, interpersonally and in society.

Examples from transcripts that highlight connection and rich data include a research focus group led by a teacher and a parent of a child with disabilities. Participants were other parents of children with disabilities at the school. They spent time listening to each other's narratives concerning each child's impairments before continuing through the research questions. They had never come together before, and they chose to hold the space for each other much longer than anticipated. By the time it came to suggesting ways forward in the community and school, they were already talking as a formed group with many collaborative ideas. In a one-to-one interview in *Hear My Voice*, Tanzania, between two people with albinism, the interviewee was able to talk frankly about horrific abuse, knowing that the interviewer understood the situation deeply.

As findings emerge from the various CBPR research projects, there are many examples of nuanced expressions of lived experiences of children, youth and adults with disabilities in the fields of social/financial inclusion and education. Although a review of project findings is not within the scope of this article, one example from the *Pamoja* research, Kenya, highlights a

quiet desire to celebrate children with disabilities in and beyond their school. Interviewees, alongside more expected responses about inclusive education needs, engaged with peer and community researchers in such a way as to share their desires about what the children being celebrated meant to them and what that might look like in each context. This was then built into the project intervention linked to SDG 4.

Main value tensions

- When CBPR research has been built into an intervention project which has a set time frame, it has been important to report back findings in time to influence the decision-making processes relating to interventions. If the data collection has been delayed slightly due to ethical permissions taking longer than anticipated, holidays or political events, analysis may need to be sped up to allow the findings to be influential. However, as peer researchers, often with disabilities, are involved in the analysis process, this is not a process to be rushed, as peer researchers' analysis might become a token offering rather than a key part of the process. This tension of priorities in relation to time poses a challenge to the speed of implementing the SDGs, which are broadly time-bound.

- Ensuring that CBPR ethical principles are fundamental to the study can be in tension with cultural norms. Ensuring venues and formats are accessible can depend on others' perception of accessible buildings, documents and descriptions, and so more careful requests need to be made. Democratic participation does not always sit well culturally, especially in relation to gender. Ensuring time to identify and reflect is difficult when more urgent practical issues need to be resolved. Debating what counts as positive change can feel uncomfortable, and stakeholders may avoid potential conflict. Ultimately, being open to challenge and change and prepared to work with conflict is often readily agreed to, but when conflict arises, how it is raised and responded to is dependent on many factors, not least habitual attitudes. Working through this tension is vital to the achievement of the SDGs. For the outcomes of an intervention and its inherent research to be sustainable, it requires the careful weaving together of the social culture, including gender norms, and that of the methodology.

- Power differentials can remain substantial and it has not always been clear to all what working towards sharing power more equally looks like in practice. Collaborative relationships with community members have allowed for navigation of disagreements, but the nuanced power dynamics are complex, particularly in relation to tribe and gender. Acknowledging and discussing differences in the status and power of those involved can be considered rude and needs to be approached carefully and consistently. How beneficial is CBPR for people with disabilities – do we know or do we think we know what is best? Finding out the answer needs to be built into the

CBPR process. The issues of power dynamics in implementing the SDGs are not addressed in the 2030 Agenda, which contributes to keeping it implicit.

Tensions can become dilemmas. The following points continue to be held in uncertainty.

Main dilemmas

- Peer researchers cannot be as included in planning as CBPR methodology requires. Once ethical clearance is granted from an in-country academic institution to begin the research, peer or community researchers can become part of the research planning process. However, to gain these permissions from an ethical board, research plans must already be in place. The aims and objectives of the research and the specific research questions leading from them are often already designed (in consultation with local stakeholders) before the peer researchers come on board. A potential way forward is described below.
- It has been difficult to know how to best include peer researchers in data analysis: involving them too much can be overwhelming for all, too little undermines ownership and involving them at a deductive stage with an inductive framework to work from seems to work best but risks being tokenistic. Furthermore, potential biases can arise through including people with disabilities as researchers (as is also the case for any community member): peer researchers come in with their own pre-conceived notions based on their personal experience, which may be heightened if they have experienced stigma and discrimination. Without careful awareness-raising in data analysis training, and a clear analysis support process, peer researchers could then reinforce these biases through their coding.
- No one with speech difficulties or intellectual difficulties has come forward to participate, despite being asked. Therefore, the successes, tensions and dilemmas of this level of inclusion are not known.

Each of these dilemmas hinders the inclusivity and participation set out in Goal 17. One solution of peer researchers being involved from the outset has been to gain a research permit from the appropriate ministry to undertake some basic consultation with community members via local stakeholders whilst developing a protocol. Going forward, as more peer researchers, country offices and grassroots organisations are skilled in participatory research, identifying precise research need and how it might proceed could be initiated locally and bids could be built on this. At the moment, peer researchers are not generating research questions due to the described limitations; whether they would struggle to do so remains unknown at this stage. Decolonizing methodology reminds us of an important lesson here: community researchers need to set the agenda for change themselves, not simply react to an agenda that has been laid out for them by others (Smith, 2012). Ways forward need to be found for ownership at the earliest stages of the process.

During initial CBPR research analysis, researchers and peer researchers worked separately and then brought their findings together (Greenwood et al., 2016). Peer researchers identified main issues in all interviews, how they were connected, and priority categories on which to focus policy and advocacy efforts. Researchers undertook three-tier coding based on grounded theory, simply coding experiences relating to disability or old age. Although the data wove together relatively well, it needed to be more coherent (see Greenwood et al., 2016). The inductive-deductive split between researcher and peer researchers has been used in recent research analysis, but it is still work in progress.

There are predicted practical challenges to the meaningful inclusion of people with intellectual impairment and speech difficulties within CBPR, but there has as yet been no opportunity to overcome them. This is a significant issue; partnering with people with visual, hearing or other physical impairments is constantly improving in the projects described, with good representation from women, whilst those with intellectual impairments and speech difficulties are not represented. To some extent, this is due to the fact that a main focus of the organisation exploring CBPR within education and social inclusion is visual impairment. It may also be due to choices as to how community members are approached in-country, which needs to be investigated. There is certainly opportunity for organisations with a focus on intellectual impairment or mental health, for example, to partner in or lead such CBPR research to fill the participation gap. The 2030 Agenda pledge to reach the furthest behind first is never more relevant than here. However, it is likely that there will be challenges in training people with intellectual impairments as peer researchers, and so such partnerships would need to be handled carefully. Further, it is unlikely that all people with disabilities would be able to be meaningfully included in this process, even with accommodations. Therefore, careful and realistic communication is vital from the outset.

In terms of future direction, collaboration between organisations committed to CBPR could build an effective network that together is able to identify key barriers to achieving the SDGs and further inform how policy and programmes can be altered to best meet the needs of people with disabilities. It could also contribute to the review and follow-up process laid out in the 2030 Agenda. Such a network could hone building the methodology within programmes, help country offices and grassroots organisations to feel empowered to co-lead on research and explore the dynamics of CBPR within a mixed method approach. Researchers with disabilities could also be involved in assisting with peer and community researcher training. Ultimately, what is central to navigating the tensions and dilemmas is, as Zavala (2013: 66) reminds us, that 'the spaces and communities that give life to these projects take precedent over question of method and strategy.'

Conclusion

This paper has highlighted an alignment between the aims of the 2030 Agenda and the nature of disability-focused CBPR. It has also demonstrated CBPR in practice in the global South and raised tensions and dilemmas that need to be acknowledged as significant, but worth the time to navigate the uncertainty to see change. It is vital to identify key barriers to and facilitators of achieving the SDGs and to include people with disabilities in the process as part of that facilitation. CBPR research is making steps to achieve this by informing how policy and programmes can be altered to best meet the needs of people with disabilities, building a picture of disparities in education, highlighting the challenges of people with disabilities in pursuit of employment, and showing how people experience disability on a daily basis, individually, interpersonally and in society.

Current CBPR research is not yet at a stage of systematically identifying those key barriers to achieving the SDGs on a large scale. However, it has the capacity to do so as a methodology, especially if a research hub is formed. There is still much to learn about this innovative research practice, which will develop further in dialogue and collaboration with others working towards disability inclusion. Despite its time-consuming nature, inclusive analysis complications and demanding ethical principles, one thing remains clear from engaging with CBPR: the 2030 Agenda objective of "leaving no one behind" will be better achieved if children, youth and adults with disabilities are participating in local, national and global research and policy making. CBPR, alongside other methodologies and activities, has the capacity to facilitate achieving the SDGs that explicitly refer to people with disabilities, those referring to people in vulnerable situations and discrimination and the Agenda as an integrated whole. However, to weave it into intervention-based projects needs all parties to understand its nature and principles, and allow it time to facilitate change amidst context and complexity. To join partners with diverse expertise requires much planning, diplomacy and critical, reflexive thought, but is essential to generate local and national ownership of findings and facilitate the translation of knowledge into a catalyst for real disability-related policy change.

Notes

[1] "Ti Kule Limodzi" (Let's Grow Together): Improving curriculum and teaching methods to influence policy and increase the quality of ECDE provision for children with disabilities in Malawi. This three year research study funded by ESRC/DfID will provide ESRC, DfID, the Malawi Government and its partners in education with a better understanding of the complex dynamics that can enable or inhibit quality early childhood development and education (ECDE) for children with disabilities. It will also develop and test tools for providing and

measuring ECDE services that will lead to improved developmental and learning outcomes in Malawi.

[2] Programmatic project "Connecting the dots": identified young people with disabilities receive basic vocational skills training, are equipped with start-up kits and actively linked to local businesses and entrepreneurs for financial services, internship or job opportunities. Specific activities range from providing medical and functional assessments to mainstreaming disability in public vocational institutions, whilst offering support and guidance to young people and institutions in training, advocacy and direction.

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