Part 3  Mapping the space of possibility for just urban development

12  (Re-)constructing disability through research

Methodological challenges of intersectional research in informal urban settlements

Julian Walker https://orcid.org/0000-0002-4790-650X and Ignacia Ossul-Vermehren, Ignacia https://orcid.org/0000-0002-4469-5268

This chapter discusses the inherent methodological tensions in doing intersectional research around disability in informal urban settlements. On the one hand, this requires methods which respect the agency of research participants in defining their own identities and portray the complex and intersectional nature of urban dwellers’ lives. On the other hand, taking the singular category of disability as an entry point can serve important functions: revealing systematic inequalities around disability, and; acting as the basis for collective mobilisation on disability rights. We reflect on how research methods can solidify, impose, challenge, or politicise categories such as ‘disability’ and explore ways of doing intersectional research, highlighting the potential of strategically sequencing categorical with anti-categorical approaches, using the case of a research project in Indonesia and Sierra Leone. This project wove both categorical and anti-categorical methods through a range of tools such as a quantitative survey, photovoice, and a textile banner making workshop. We make the case that the category of ‘disabled’, in a context of urban informality, is not enough to understand participants’ priorities, showing the need to work critically, not only with identity categories, but through them, and to engage in practices of solidarity amongst residents.

Introduction

In the same way that initiatives aiming at inclusive urban political participation centre on the representation of defined categories of urban citizens such as youth, women, or disabled people, participatory research that aims to reveal diverse experiences of the city tends to be structured around the participation of different ‘categories’ of people in research. While the inclusion of diverse voices and perspectives in research is a crucial starting point in ensuring that the experiences of less powerful city dwellers are represented in research, understanding experiences of the city through the prism of singular categories of identity is problematic. It can be: reductionist, eliding the multiple and contingent identities of research participants such as ‘women’ or ‘disabled people’; prescriptive, in labelling specific identities as more important and denying research participants agency in defining their own identities and ascribing importance to them in particular contexts, and; potentially, divisive, in emphasising the different experiences and priorities of ‘identity groups’ at the expense of revealing shared relations and collective priorities that cut across identities.

However, such markers of collective identity can have an important function in urban research. On the one hand, it is critical for research to engage with the persistent inequalities manifested
spatially and socially across cities, which can also be mapped across axes of identity. On the other hand, collective identities based on factors such as disability, race, or gender play an important role in fostering a set of shared political claims in challenging urban inequalities, and research, by fostering collaboration, and providing a knowledge base and space for reflection around the pertinence of such collectives can, and should, contribute to the building of identity based political formations.

Although intersectionality is well developed as an area of theory, there is less work on intersectionality from a methodological perspective (Goethals, De Schauwer & Van Hove, 2015). In this chapter, we reflect on how research methods can solidify, impose, challenge, or politicise identities such as ‘disability’ and explore ways of doing intersectional research, highlighting the potential of strategically sequencing categorical with anti-categorical approaches. We argue that categorical approaches are needed to reveal structural and persistent identity-based inequalities and consolidate political consciousness, alongside anti-categorical approaches that aim to respect the agency and complexity of individual research participants. The methods discussed in this chapter derive from a research project focused on community-led responses to assistive technology¹ (AT) users’ needs in four informal settlements, two in Freetown, Sierra Leone, and two in Banjarmasin, Indonesia.

Disability and urban inequalities

Disability, as a parameter of social identity, is highly associated with inequality in development outcomes (Groce & Kett, 2013). It is also widely manifested: according to the World Health Organisation, 15% of the global population has a disability, accounting for one of the largest ‘minority groups’ in the world (World Health Organization, 2011).

The understanding of the inequalities linked to disability is strongly associated with the competing ways in which it has been defined. Challenging the ‘medical model’ which equated disability with the physical/medical limitations associated with disabled people’s bodies, the ‘social model’ (Barnes, 2000) argues that disability is caused not by people’s impairments, but rather by discrimination, and society’s failure to accommodate these impairments and the specific needs associated with them. As expressed by Finkelstein (1980), therefore, “disability

¹ The World Health Organisation defines assistive technologies (AT) as the “the umbrella term covering the systems and services related to the delivery of assistive products and services”, which are products that “maintain or improve an individual’s functioning and independence, thereby promoting their well-being”. Examples of Assistive Products (AP) can be hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids.
is the outcome of an oppressive relationship between people with impairments and the rest of society” (p. 47).

However, the social model of disability has been critiqued for underplaying the very real role of impairments on the lives of disabled people (e.g. dealing with pain, and the need for rehabilitation or assistive technology). The bio-psychosocial model has been presented as a way of integrating the physical, embodied aspects of disability with societal factors (Shakespeare, 2014). Drawing on this, the definition used in the World Report on Disability: “understands disability as dynamic integration between health conditions, contextual factors, both personal and environmental, promoted as the bio-psychosocial model” (World Health Organization, 2011, p. 4).

The bio-psychosocial model, taking a person-centred approach, emphasizes the importance of understanding disability as a continuum, with impairments only a part of the determinants of the range of abilities of each person, which constitute the human condition, and which vary between all individuals and vary across our life-cycles. Similarly, researchers approaching disability through the lens of the capability approach (e.g. Baylies, 2002; and Mitra, 2006) frame disability as one of multiple factors which may inhibit people’s capabilities: “An individual is disabled if he or she cannot do or be the things he or she values doing or being” (Mitra, 2006, p. 241).

At an urban scale, building on the contribution of the social model, and the integration of its socio-political focus into the bio-psychosocial model, researchers have argued that the spatial structure of cities reproduces dominant power relations, contributing both in highly visible, and more subtle ways to the oppression and exclusion of disabled people (Imrie, 1996; Hamraie, 2013).

Some of the most prominent responses to the issues faced by disabled people in cities have focused on the emblematic issue of accessibility. Principles of inclusive, and universal, design have:

(…) showed that the design of buildings is not a value-neutral and passive act; rather, the design of the built environment actively conditions and shapes the assumptions that the designers, architects, and planners of these value-laden contexts hold with respect to who will (and should) inhabit the world.

(Hamraie, 2013, p. 2)
Other manifestations of disability inequality in cities may be less physical/spatial. For example, Ellen Clifford from the UK Disabled Peoples’ Organization (DPO) ‘Disabled People Against Cuts’ (DPAC) highlights the impact of austerity and associated cuts in social services on urban segregation and the consequences for mental health and its visibility:

(...) the Mayor’s recent initiative ‘Thrive London’ takes a very individualistic approach; it talks about equipping Londoners to manage mental health but doesn’t acknowledge that some people will need support or that people’s situations are aggravated by benefit cuts. (...) One of the impacts of the cuts is that people are trapped in their own homes, which makes them even more invisible, creates segregated communities.

(Clifford, 2020, p. 73)

A prerequisite for more inclusive cities, to challenge the disabling effects of ableist city-making, is efforts to promote representation of disabled people in urban decision-making for structures of governance. The slogan “Nothing about us, without us” has been a political tool in the disability rights movement, challenging the practice of non-disabled actors and institutions of speaking on behalf of disabled people. However, this focus on the political representation of disabled people is not without challenges. Firstly, a question is how best to link disabled people’s political claims with wider urban citizenship struggles. Efforts to present disability as part of a wider continuum, rather than a disabled/non-disabled binary, has an important political function in not casting disabled people as ‘other’ and in mainstreaming disability concerns into wider development processes. Linked to this, many disabled people rely significantly on support from carers, and so often enact agency and make decisions with and through these carers. As Shakespeare (2014) notes, the focus in the UK on providing personal assistance for disabled people frequently emphasises personal assistants’ role in ensuring the independence/autonomy of disabled people while under-emphasising the emotional relationship between carers and disabled people. A very strong emphasis on disabled people’s individual agency, to the exclusion of their relational agency, may therefore be misleading and, as a corollary, it may be important to understand their shared interests with carers and with other, non-disabled, people.

However, efforts to emphasise the links, similarities, and shared interests of disabled and non-disabled people may also obscure the specific issues that disabled people face presenting ‘disabled people’ as a collective with a shared set of claims can have an important political
function. Clifford (2020), talking about the work of DPAC in the UK highlights that “(…) collective resistance and action are very important. Disabled People Against Cuts creates a space for people to come together and support each other and that gives people a sense of hope” (p. 73).

On the other hand, it should not be assumed that disabled political actors and collectives necessarily represent the spectrum of ‘disabled people’s needs’. The issues faced and priorities valued by disabled people are based on multiple and dynamic identities (e.g. for disabled children, gender identity may be more important in achieving some valued life outcomes than disability) (Walker, Frediani, & Trani, 2013). Furthermore, as is evidenced by the often fragmented nature of the disability movement, people with disabilities may have very different priorities, and there are frequently hierarchies of power and status across different disabilities. For example, within the disabled community in many contexts people with visual impairments are afforded greater status than people with other types of disability, such as those linked to cognitive impairments (this was the case in both of our research sites). A key question regarding the collective agency of disabled people, therefore, is how to foster a shared political agenda without either ignoring the diversity of disabled people, or presenting ‘disabled’ and ‘non – disabled’ people as though they were two distinct and de-linked categories.

Disability, identity and research methods

Given these concerns around how disability as an identity can influence processes of political representation, it is important to reflect on how research methods solidify, impose, challenge, or politicise, categories such as ‘disability’.

A common shortcoming in research is that disabled people are assumed to share the same experiences, and priorities, regardless of gender, age, cultural background, sexual orientation and other categories of difference (Goethals et al. 2015; Garland-Thomson, 2005). To counter such problems, it is helpful to draw on scholarship which addresses how, and by whom, identity based categories are assigned in research methods. Defining people with disabilities solely based on the nature of impairments fails to explain how the experience of disability is woven through individuals’ multiple identities as much more than the addition of classism, racism, and sexism. There are two classic approaches to dealing with multiple identities (Purdie-Vaughns & Eibach, 2008): The additive model, which adds different marginal subjects’ experiences, and the intersectional approach.

The additive approach presents the distinctive forms of oppression associated with multiple subordinate identities as summed together. The more devalued identities a person has, the more
cumulative discrimination they are assumed to face. For example, if women tend to get paid less and disabled people are less likely to get a job, being a woman and disabled is a double disadvantage for earning income. Alternatively, researchers advocating an intersecting approach explain how a person’s subordinate identities interact in a synergistic way, which may lead to specific forms of oppression rather than doubling mainstream disadvantage. For example, a disabled pregnant woman who is advised to terminate her pregnancy, faces specific discrimination based on societal assumptions about the kind of mother that she would be, which is distinct from discrimination faced by other women, or disabled men.

Although there is an important body of theory on intersectionality, there is less academic work on intersectionality from a methodological perspective (Goethals et al., 2015; Nash, 2008). McCall (2005) offers three methodologies to deal with intersectionality: intracategorical, intercategorical and anticategorical approaches. An intracategorical approach takes the experiences of multiple subordinated groups (e.g. black women) as the entry point to understand the complexity of categories. In contrast, an intercategorical approach is focused on the relationship of inequality between different groups. An anticategorical approach argues that categories are too simplistic, and reproduce problems that the concept of intersectionality set out to challenge in the first place. Instead, anti-categorical approaches such as narrative accounts and life stories allow research subjects to interpret their own experiences and the salience of specific identities in these, rather than having a focus on specific identities imposed by a researcher, or a research method (Prins, 2006).

However, while an anticategorical approach responds to the problematic nature of disability as a category of identity, as discussed earlier, the adoption of disability as a collective political identity requires that disability is understood as a unifying category, even if recognising its intersectional and fractured nature. In this vein, while recognising their contribution, Shakespeare (2014) critiques some of the poststructuralist approaches of authors from the Critical Disability Studies school (such as Dan Goodley, Helen Meekosha and Russell Shuttleworth) on the basis that “Scholars sometimes appear more concerned with deconstructing the category of disability (…) than in changing the social conditions of disabled people (…)” (p. 2). By adopting (reflexively) disability as a category, research with an ‘action’ intention can aim to support disability politics by making disability more visible as a basis for inequality, as well as providing a space of conscientization and valorisation of disability as an identity (which is important where disability is associated with a high level of stigma).

In conclusion, urban research around disability requires engagement with two complex tensions relating to the interplay of issues of categorisation, intersectionality, and agency:
The category of ‘disability’ is needed to reveal pervasive structural inequalities, and as a basis for collective political claims. However, this category is fractured by internal differences and hierarchies between different disabilities, and external intersections with other identities which influence different experiences of disability.

The experience of disability must be understood from the perspective of disabled people, rather than as an imposed, essentialised label. However, in a context of stigma, many disabled people can be hesitant to recognize disability as an important part of their identity, and mobilising disability as a political identity may depend on some level of external inputs or provocations around the salience of disability-related inequalities.

The following section of this chapter will document our attempts to engage with these tensions in the frame of a specific research project. The methodology we present used a phased mix of categorical and anti-categorical approaches and as such we feel it is in line with McCall’s (2005) concept of intercategorical complexity which compels scholars to “…provisionally adopt existing analytical categories to document relationships of inequality among social groups and changing configurations of inequality along multiple and conflicting dimensions” (p. 1773).

A project on community led solutions for assistive technologies in informal settlements

The research project in which we have attempted to engage with the methodological challenges outlined focuses on community-led responses for assistive technology (AT). It is a collaboration between the Bartlett Development Planning Unit-University College London, Leonard Cheshire International2 (UK), the Sierra Leone Urban Research Centre3 (Sierra Leone), and Kota Kita4 (Indonesia). The overarching research question that the projects aims to understand is “How can collective, and community-led responses, empower disabled people to access better life outcomes, through increasing the relevance and uptake of AT?”

The research project was conducted in four urban low-income communities, two in Freetown (Sierra Leone) and two in Banjarmasin (Indonesia). Phase 1 of the research, which was undertaken between August and December 2019, mapped out how local residents in the four settlements are able to pursue a number of shared aspirations that they have collectively identified as priorities.

2 Leonard Cheshire is a leading inclusive development agency working to improve the lives of persons with disabilities in developing countries.
3 SLURC is a globally connected research centre focused on the well-being of residents of informal settlements in Sierra Leone.
4 Yayasan Kota Kita Surakarta is a non-profit organization with expertise in urban planning and citizen participation in the design and development of cities in Indonesia.
The research was undertaken with 30 adult residents from each informal settlement, 120 people in total across the two cities. We selected more ‘mainstream’ settlements of the urban poor rather than settlements characterised by a high prevalence of disability. The research used collective participatory methods, individual qualitative methods and a quantitative survey on AT need and access was conducted, using the World Health Organization (WHO) rATA (Rapid Assistive Technology Appraisal) tool, covering the broader community (just over 1,000 people in each settlement).

Research methods and mixed approaches to categorization.

The following sections present how our research design aimed to address the tensions of undertaking intersectional disability research in the settlements by sequencing categorical and anti-categorical approaches.

i] Categorical approaches: Identifying disabled people as a category to ensure inclusion and highlight shared experiences of inequality

As a starting point, the research study explicitly used disability as a category in two ways: as a criteria for selecting research participants, and as a unit of analysis in the rATA survey. The first phase of the research project aimed at identifying aspirations of residents, some of them disabled and AT users. We used a categorical approach to select participants in each community, broadly 50% disabled people, 25% AT users (or potential AT users) and 25% non-disabled residents, with a balance of male and female, and a range of ages. Amongst the disabled participants we aimed to ensure a mixed representation across a range of disabilities, which involved making some accommodation to ensure that the research activities were accessible (providing sign language interpretation, accessible venues, and including carers in research activities where relevant). Balance amongst other social relations such as ethnicity and religion were promoted, but not strictly applied.

In terms of forming disability as a category, participants were identified as disabled and/or AT users through self-declaring, referral by community members, and through being identified via the rATA survey. Self-declaration has evident limitations as it is dependent on what is understood as disability in a given context, and stigma in the communities may affect willingness to self-declare as disabled. In addition, lack of knowledge of AT can reduce the likelihood of people self-declaring as a potential AT user (i.e. someone who would benefit from an assistive product but does not have it).

In view of this, the rATA survey helped to identify disabled people and AT users who did not self-declare or were not referred by other community members. The rATA is a self-reported
survey designed for rapid evaluation of the need, use, supply and impact of Assistive Technology. While it does not ask respondents to self-identify as ‘disabled’ it uses the Washington Group Short Set of Questions\(^5\) to estimate prevalence of disability across six domains (seeing, moving, communicating, self-caring, remembering, and concentrating). It deals with stigma issues of self-declaration by explicitly not referring to ‘disability’, but instead asking how difficult respondents find tasks without the help of an assistive product (e.g. *Do you have difficulty seeing without spectacles?*). This allowed us to identify people with a high level of functioning difficulty and/or existing AT users, even if they did not self-identify as disabled, and invite them to participate in the research. Also, by inviting people identified through a household survey (instead of through community leaders) many people that tended to be less active, specially older people or isolated disabled people, joined a public forum for the first time.

While recognising the dangers of a categorical approach discussed earlier, we felt that a specific targeting to recruit disabled participants was a necessary starting point for this project. The research study is specifically focused on disability and AT use, but worked through mainstream community organisations which had limited experience working on disability and recruiting and working with disabled people in participatory research. In addition, the settlements had a high level of stigma around disability, and disabled people (albeit with some exceptions) in the four communities tended to be less well represented in community organizations. Thus, taking a categorical approach responded to the danger that disabled participants would otherwise not have been well represented in the participant group.

In practice, recruiting disabled participants required specific actions; participants were visited several times in their homes to discuss the research individually and create a rapport. Grass-roots and partner organisations also worked to establish a relationship of trust with many of the participants, who slowly decided to come to the workshops. Methods were also adapted – for example, in the photovoice study (discussed below) disabled participants were given the cameras in their homes if they did not feel confident in attending the photography workshops. Non-disabled participants, on the other hand, were self-selected individuals who expressed an interest in the research, and did not need specific encouragement to join – the only proviso with regards to their involvement was that they had to be mixed in terms of age and gender, and could not hold a position of power in the community (this was a choice made to avoid creating

\(^5\) The Washington Group Short Set of Questions on disability is an internationally recognised disability question set consisting of six questions that ask about difficulties conducting everyday activities. For further information, see: [www.washingtongroup-disability.com/](http://www.washingtongroup-disability.com/).
a power imbalance amongst participants, as, apart from a few exceptions, none of the disabled people and AT users had experience in a community leadership).

The second use of disability as an explicit category was in the analysis of the rATA dataset. The rATA survey both asks for basic demographic data of respondents (age, sex) and uses the Washington short set questions as an indication of functional difficulties/AT need. We used a cut-off ranking to identity respondents declaring high level of difficulty carrying out tasks in one or more domain (‘a lot of difficulty’ and ‘cannot do at all’) as disabled. This allowed us to pick up patterns or prevalence of disabilities as well as the different experiences in relation to access to ATs.

For example, the rATA survey identified a high level of functional difficulty for 4.3% of respondents in the Freetown settlements, which compares to the Sierra Leone 2015 Population and Housing Census conducted by Statistics Sierra Leone (SSL) (Kabia & Umaru, 2017), which puts the national prevalence of disability at only 1.3% of population. This kind of data plays an important function in terms of advocacy, particularly for national DPOs who have long been questioning the undercounting of disability in national census data.

The rATA also highlighted the low AT coverage in the communities targeted. In Freetown only about a third of individuals who experience a lot of difficulty in one or more domains (35.4%; N=29) and just over a fifth who cannot function at all (22.2%; N=2) have access to assistive products. A key purpose of the rATA survey tool is to highlight the significant unmet need for assistive products. Generating this kind of evidence that relies on targeting disabled people as a category has a crucial advocacy purpose.

In addition (although these findings were made less statistically significant by the relatively small sample of disabled people in the overall survey population of around 4,000), combining the WG Short Set questions with the basic demographic data in the survey allowed for a certain amount of inter-categorical analysis to examine the intersection between disability and gender. This highlighted, for example, the importance of gender as a factor intersecting with disability in Freetown where the access to assistive products was higher for men, especially in the case of respondents who answered ‘cannot do at all’ (33.3% of men versus 0% of women).

ii) Anti-categorical methods to focus on the intersectionality of person-centred experiences

While the process of identifying participants for the core group used disability and AT use as categories to recruit participants, the methods used for the qualitative research to map out shared aspirations were anti-categorical. When engaging participants in the collective research
methods, all participants were asked the same questions and used the same methods, and no direction was given to participants around referring to their experiences as disabled or non-disabled.

The research methods used included activities that were designed to give participants space to identify areas in their lives that they value by producing individual outputs which they could share with the rest of the group, which did not rely on written or verbal skills. We aimed to use methods drawing on multiple forms of knowledge generation including, for example, visual methods such as photo elicitation (Ossul-Vermehren, 2018; Rose, 2016) and textile making. This was in an effort to address the ‘cognitive injustices’ faced by some disabled people, and at the same time to use individual methods which put the participant at the centre of their story. As Goethals et al. (2015) state “(…) [narratives of lived experiences] are helpful in reclaiming the stories of people with disabilities as suitable research material and allow differences among these experiences without the problematic emphasis on the universality of them.” (p. 83)

The methods used included a photovoice workshop (using digital cameras given to participants over a couple of days), shadowing (in which individuals could show researcher things they valued in their home, neighbourhood or city), and photo essays through which participants instructed a professional photographer to capture images depicting activities, people or places that are important to them. What these three methods had in common is that the participants were in control of the images that are shown (photovoice and photo essay) and the places that are visited (shadowing), and the guiding questions were open enough to allow participants to lead the process.

These anti-categorical methods engaged with intersectionality by giving the space for participants to highlight different aspects of their identities and lived experiences which they felt were important factors in determining both the nature of the aspirations and their ability to realise these aspirations. They allowed for the analysis of the salience of different sources of identity both by the participants themselves and, through the coding and analysis of the results, also allowed the researchers to pick up patterns of experience across identities that were not highlighted by participants.

For example, in the shadowing interviews and photovoice in Banjarmasin, residents discussed the aspiration of ‘Social Solidarity’ which they had previously identified as a shared priority. This was defined by participants as caring for others in the neighbourhood, having awareness of other people’s needs, and helping those facing difficulties.

Two female participants joining this activity who both have a mobility impairment illustrate how participants highlighted different aspects of their identity. The first, a woman in her sixties
who is an active community member, engages in activities that support other disabled people (she is the local head of the national women with disabilities association, a Paralympic committee member, and the leader of the neighbourhood waste bank). The second, a woman in her twenties, mostly stays at home, because she finds mobility outside the house difficult, and because her parents are protective of her going out on her own. During the shadowing interview, both participants were asked: “What are the barriers that stop (or make it difficult) for you to achieve this aspiration?” The younger woman highlighted her disability as a key barrier for socialising. She explains:

I’m afraid to take a ride on it [boat], because of my feet condition I can’t swim. I almost drowned a while ago. It was very traumatic so I’m afraid to take it again, but I really wish I could. I want to go to Kembang Island, see monkeys, visit religious places, meet friends.

The older woman highlighted the clash between her multiple activities and the weather, as rainfall makes it more difficult to get a motorbike taxi. She did not mention her own disability as a barrier, but highlighted her community work and her role helping others, especially other women. This gives an indication of how she perceives herself, and the role that being disabled plays in her social activities.

In addition to seeing differences between how some participants self-identified, or not, as disabled in relation to a specific aspiration, another interesting pattern that emerged was the ways in which participants linked some aspirations to disability far more than others. For example, during the shadowing exercises in the settlement of Dworzarck, Freetown participants’ strategies towards the aspiration of ‘Affordable Housing’ focused very much on the generation of income and education as a route to generating income to secure decent housing. Reference to disability was rarely made, with the exception of one disabled respondent who had to care for her disabled mother and highlighted that support to her caregiving role would help her in freeing up more time for income generation and help her access housing.

In contrast, participants in Thompson Bay, Freetown, discussing their strategies towards ‘Inclusive Mobility’ made frequent references to disability, also highlighted in the pictures they took and the shadowing exercise. These related to the terrain (for example, the steep hill to the main road access point at Indian Temple) and also to the lack of reliable assistive products as one female participant explained through one picture she took of herself moving in the settlement: “My crutches are broken and the surroundings are rocky and slippery”. Others also
referred to discrimination against disabled people as a barrier to transport use, including from transport providers (taxis and motorbike taxis not stopping for disabled people) and other users (mocking disabled people). However, while some participants did not refer to disability, their circumstances can generate lessons for disability inclusive urban services. For example, Maria (pseudonym), a young woman from Thompson Bay who has a hearing impairment, goes to work every day to the city centre. The shadowing exercise showed that she does not encounter major difficulties in her daily commute. Her bus goes to her workplace, and she gets off in the last stop. This bus is unusual amongst Freetown transport options in having a fixed route and fare, which means that she does not need to talk to public transport providers to negotiate the fee or check the route. As a result of the way this bus service works, she did not consider her disability as a barrier to mobility.

At the same time, it was also important to note other facets of identity that our research group highlighted as influencing their aspirations and how they pursue them. In both Banjarmasin and Freetown, religious identity was a highly important factor for many of our participants, as was being a parent, and this was a key determinant of many of their strategies toward achieving specific aspirations. Such information is also critical for developing relevant interventions for urban development or AT access as they give insight into people’s own motivations as well as their collective affiliations through which interventions may best reach them or work with them.

iii) Re-constructing categories. Collective reflection to make visible and validate disability as a collective identity.

Photo 12.1 Participants in Freetown, Sierra Leone holding textile banner on Inclusive Mobility.

Source: Angus Stewart

Finally, in addition to using disability as a category to identify participants, and collect and analyse quantitative data, the final method in this research phase aimed to use the research interactions as a space for participants to engage with and (re)construct disability as a shared parameter of identity. In this phase, prioritising disability as a visible category allowed participants and researchers to understand the common barriers for disabled people, in terms of discriminatory social institutions which underpin disabled people’s experience of the city, and, by working with a majority of disabled people and AT users, it aimed to create a space for disabled people to express agency and share common experiences.
This effort was conducted through a number of activities. Building on the previous phases through collective analysis of the outputs of the methods outlined above, participants were encouraged to work together to decide which were the most representative aspirations for the community in general, as well as the most transformational for disabled people in particular. This made it possible to identify the barriers and enablers to achieving those, and the collective and individual resources they had or use. In Freetown, participants in each community created a textile banner with images of the aspiration chosen and what it represents for the collective.

In the four communities, in both Indonesia and Sierra Leone, the aspirations chosen by participants were shared across non-disabled, AT users and disabled residents. All the aspirations selected (e.g. access to more public spaces; mobility in the settlement and city; access to affordable housing; healthy and safe living conditions) reflected a shared experience of inequality in the city, showing that the category of ‘disabled’, in a context of urban informality is not enough to understand residents’ priorities and needs. Importantly, furthermore, the aspirations also pointed to the need to critically work not only with identity categories, but through them, and to engage in practices of solidarity amongst residents.

However, some of the specific ways in which the aspirations were experienced and pursued were unique to disabled participants. For example, in Kelayan Barat neighbourhood (Banjarmasin), residents identified the need for a public space, a need which was common across social identities, and was expressed as a need for the wider community. Despite this, discussions highlighted the need for space that is physically accessible and inclusive, as many disabled residents and older people spent most of their time at home and would benefit from a social space. One of the disabled female participants explained: “For someone having difficulties, like me that I have difficulty walking, I cannot access some of those spaces. I would like to be outside, but instead I stay inside and watch television all day.”

Collective analysis among disabled and non-disabled participants served two aims. First, analytically, as stated above, it helped to understand the nature of residents’ aspirations; whether they are grounded on participants’ experience as disabled residents and/or more widely as residents of informal settlements, and linked to wider issues of urban inequality. Secondly, it was also a political decision; bringing together residents who may have never worked together and having them decide together on collective aspirations served the aim of making disabled peoples’ needs and aspirations more visible in the wider community in the hope that they would be taken into mainstream community actions.

In the case of Banjarmasin, the local organizations, Kaki Kota and Kota Kita were already working with the city government on an inclusive cities’ strategy. However, in the case of
Freetown, the project was working with the Federation of the Urban and Rural Poor/ FEDURP (the Sierra Leone chapter of Slum Dwellers International) and the involvement of FEDURP in the research study, both as field researchers and with FEDURP members as participants, began to have an impact on their approach to including disabled peoples’ priorities with wider urban issues of informal settlements in the city and their associated campaigning.

The research project was used to introduce a language of disability to FEDURP, referring to ‘disabled people’ and challenging the existing vocabulary which local DPOs critique as offensive, pejorative, or patronising. There was a continuous process of training and mentoring FEDURP members in specific methods and tools, as well as in how to work with disabled participants. These served as reflexive spaces for FEDURP members to identify how they could mainstream disability in the day-to-day work of the federation. The FEDURP leadership themselves felt that the research had influenced the way that they worked with disabled residents: “We knew that disability was a big issue, but we hadn’t engaged with it, either including disability in the discussion nor working with disabled residents specially. FEDURP is now committed to working with people with disabilities.” (FEDURP country head, speech during the Celebration of International Day of Persons with Disability, December 5th 2019)

At the same time as promoting the visibility of disabled people in wider community initiatives, such as those of FEDURP, another intention of emphasising disability as a categorical identity through the research project was to support its redefinition as a positive collective (for disabled people themselves and for the wider community). Phase 1 of the research study has showed that the on-going research activities in the communities, implemented through grassroots organisations and with a participatory approach, can facilitate an emerging collective and positive identity around ‘disability’. Many participants who before did not want to refer to themselves as disabled, started to see disability as a more positive, political, group identity, and we aimed to foster this change through building inputs into visible community actions. A key event to this end was using the celebration of International Day of Persons with Disability to publicly launch the work of the core group of participants, including the unveiling of the textile banner which displayed the aspirations created collectively by all participants. Importantly, this event was also used to invite, and have public presentations from, national disability activists.
Table 12.1  Mixed approaches to categorization and benefits for the research

<table>
<thead>
<tr>
<th>Approaches to categorization</th>
<th>Description and role in the research</th>
<th>Methods used</th>
<th>Benefits for the research</th>
</tr>
</thead>
</table>
| **Categorical approaches**  | Criteria for selecting research participants, and as a unit of analysis of the quantitative dataset derived from the rATA survey. | 1. Self-reporting disability  
2. Community leaders identified participants  
3. rATA survey asking respondents to self-declare functional difficulties linked to disability/ AT need. | Identifying disabled people as a category to ensure inclusion and highlight shared experiences of inequality. Avoid the dangers of not being well represented in the participant group. |
| **Anti-categorical approach** | Individual methods used for the qualitative research to map out shared aspirations. | 1. Photovoice exercise  
2. Individual shadowing  
3. Photo essay with Professional photographer | Participants express their own experiences and priorities and make their own analysis of how, and in what contexts, this links to their multiple sources of identity. They are in control of the images that are shown (photovoice and photo essay) and the places that are visited (shadowing), and the guiding questions were open enough to allow participants to lead the process. |
| **Reconstructing categories** | For advocacy and validate disability as a | 1. Textile banner making  
2. Celebration of Disabled People’s Day | Collective reflection allowed to make visible and validate disability as a }
Conclusions

Inclusive urban research is confronted by the tension between two approaches to disability as a category. On the one hand, there is a need to make disability visible, both as a category of analysis, in order to reveal structural and pervasive inequalities faced by disabled people, and as a political identity shared by those who aim to challenge these inequalities. On the other hand, there is a need to recognise that disability as a singular identity can be essentializing and neglecting of the subjectivities of disabled people. This can oversimplify what is in fact a fractured and often hierarchical set of identities, and can fail to explore the ways in which disability intersects with them.

The chapter has introduced some of the challenges faced when doing intersectional research. While such challenges are highlighted in the literature, less work has been done on how to address them both conceptually and in practice when working with low-income urban communities. By reflecting on the multiple methods used, the chapter engages with these challenges and analyses how different methods have been strategically deployed by sequencing categorical with anti-categorical approaches. Categorical approaches intended to make disability visible as a source of identity by using data to reveal patterns of inequality and to change the way that disability is seen as a social status both by disabled people and their wider communities. The anti-categorical approaches aimed to ensure that disabled people were able to present their own experiences, aspirations, and identities without assuming that a particular understanding of disability was central to it.

A third outcome in the research study was the identification of the role that the methods and the research process can have on participants and their wider community by showing disability in a positive light, and challenging stigmas attached to it. As highlighted by intersectional research and an inclusive approach in disability studies, it was possible to see how the creation of solidarity and strategic alliances among and between disabled and non-disabled residents could begin to alleviate social exclusion and marginalization.

Overall, the chapter offers a proposal for addressing what McCall calls ‘intercategorical complexity’ by using a phased mix of categorical and anti-categorical approaches. The
The relationship between different groups, in this case disabled, non-disabled, and AT users, is the entry point to discuss inequality, instead of ‘disability’ in itself. By doing this, the chapter exposes the inequalities between different groups and recognises that some of the inequalities faced are not specific to disabled people, but relate instead to wider socio-economic disparities experienced by informal dwellers in the city. That the category of ‘disabled’, in a context of urban informality, is not enough to understand residents’ priorities shows the need to work critically, not only with identity categories but through them, and to engage in practices of solidarity amongst residents.

References


