



Participatory Toolkit

Researching Accessibility, Disability
& Neurodiversity

Dr Jane Lewis

The Centre for Applied Research in Empowering Society (CARES) is a multi-disciplinary group of academics, located within London Metropolitan University, joined by our dedication to applied research and knowledge exchange with public institutions, community groups, third sector organisations and socially responsible businesses. We support London Metropolitan University's commitment to the sustainable development agenda by taking a multidisciplinary approach to tackling social problems.

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1. Context - Our Starting Point

This Toolkit draws on experience of conducting participatory research with local partner organisations (the National Youth Theatre (NYT), and London Boroughs of Islington and Haringey) and people with lived experience of disability and/or neurodivergence, on the barriers disabled people face in accessing employment and cultural activities.

This research fits closely with the LondonMet Lab thematic challenges, particularly Discrimination but also Poverty and Deprivation and Social Wealth. The three projects examine the structural inequalities and discrimination disabled people face in accessing employment, particularly skilled and well-paid employment, and in accessing cultural activities and venues.

1.1 Employment Gap between Disabled and Non-Disabled People

There is a significant employment and pay gap between disabled and non-disabled people. Nationally, one in five people have a disability. According to the Equality Act (2010), people with disabilities are protected against discrimination in the labour market, and the employer and educational institutions must make ‘reasonable adjustments’ to support disabled people participating in education and work. However, disabled people experience lower employment rates, higher unemployment rates and lower educational attainment than non-disabled people. In 2024, the employment rate for non-disabled people was 82%, as compared with 53% for disabled people. In other words, the disability employment gap was 29% (DWP, 2024).

In addition to the employment gap, there is also a significant disability pay and skills gap. Overall, disabled people are more likely to work in health, retail and education, in lower-skilled occupations, part-time jobs, and in low paid and zero-hours contract jobs with fewer career opportunities than non-disabled people (Collinson, 2024).

In Islington, it is estimated that 15% of the population has a disability, (in Haringey the figure is 14%), but that only 49% of the working-age population with a disability are in employment while 51% are not in work. Overall, in Islington, the employment rate for disabled people is 48.8% as compared with 80% for non-disabled people. The largest proportion of people out of work in Islington are people with mental health conditions (28% of working age out of work disabled population), followed by people with long standing and physical impairment (26%), neurodiversity (11%), sensory impairment (4%) and learning disabilities (3%). Similarly, in Haringey an estimated 35% of disabled people not in employment have a mental health condition.

1.2 Disability Gap in Cultural Access

Recent data also indicates that there are large differences between disabled people and non-disabled people in terms of access to culture and cultural events and venues. For example, in 2023/4, there was a 14-percentage point difference between

disabled people and non-disabled people attending a film at a cinema (45% and 59%, respectively) and large differences between disabled and non-disabled people attending a theatrical performance (34% and 43%, respectively) and live music (32% and 42%, respectively) (McAndrew et al, 2024).

1.3 Social Model of Disability

The gaps between disabled and non-disabled people's employment levels or participation in cultural events can best be explained by reference to the Social Model of Disability. There are very different models and understandings of disability which are reflected in the literature and in disability research. One key, critical approach is the Social Model of Disability (SMD), in which it is argued that disability reflects society's structures and barriers, rather than a person's impairment or difference. The Social Model of Disability underpins the three research projects discussed in this Toolkit.

The Social Model of Disability stands in contrast to and was developed as a critique of other disability frameworks such as the Medical Model of Disability (MMD). Shape Arts made this short animation about the social model of disability and argues:

‘Under the Social Model, disability is framed as a social construct created by barriers which can be changed and eliminated, providing a dynamic and positive model which identifies the causes of exclusion and inequality and proposes a solution. It is on society to make changes, not on the disabled person; for individuals and organisations to understand and then make the adjustments required to stop marginalising and excluding people whose bodies and minds don't comply with society's idea of what is normative and acceptable.

The Social Model makes a clear distinction between impairment (a condition, illness or loss/lack of function) and disability (barriers and discrimination). It also demonstrates that people from different impairment groups, far from having separate issues and interests, face common problems - such as lack of access to information and communication, environmental exclusion and discrimination in employment - and empowers them, along with their allies, to find common solutions to remove these barriers. It moves away from a position of 'blaming' the individual for their 'shortcomings', argues that impairment is and always will be present in society, and suggests that the only logical outcome is to plan and organise society in a way that includes, rather than excludes, disabled people.’ (Shape Arts, n.d).

1.4 Research Projects

This Toolkit is based on experience from conducting participatory research projects with disabled people commissioned by local external partners over the period 2022 and 2025 and includes:

- Research projects in Islington and in Haringey – which focus on the employment gap between disabled and non-disabled people and on highlighting the barriers disabled people experience in accessing both employment and employment support services.

- National Youth Theatre (NYT) project – focused on increasing young learning-disabled people’s access to cultural activities as a means of increasing confidence, reducing social isolation and increasing contacts between disabled and non-disabled young people.

Each of the projects used participatory research methods in which people with lived experience of disability played a central role. Participatory research methods were used to ensure the voices of disabled people were heard and recorded and fed back to relevant services and organisations. The aim of the participatory methods used was to seek to ensure that the research process was empowering to disabled people (Felder, 2025).

2. Islington Disability Employment Project

2.1 Aims of the Research

The aim of the Islington Disability Employment Project, conducted by London Metropolitan University in partnership with the London Borough of Islington from 2022-24, was to identify levels of unemployment among residents with different disabilities in the Borough and identify the main barriers to accessing employment and the extent to which existing employment services support disabled people getting into work. The research questions and methodology used are highlighted in the table below:

Research Question	Methodology
How many Islington residents have disabilities and long-term health conditions, and what kinds?	Quantitative data – ONS, DWP, NHS and LB Islington
What is the extent of unemployment among Islington residents with disabilities and long-term health conditions including how/if rates vary according to nature of disability.	Quantitative – as above
Intersectionality: to what extent do factors such as age, gender, ethnicity and sexual orientation affect employment rates among residents with disabilities or long-term health conditions?	Quantitative – as above
What is the availability of employment support for residents with disabilities and long-term health conditions – including the extent to which some kinds of disabilities and conditions are better or less well catered for?	Quantitative – LB Islington - plus mapping of employment support services and 1 focus group with employment advisers and service providers
To what extent are support services effective at supporting those with disabilities/health conditions into work when these residents enrol or register on programmes?	Qualitative – 5 participatory focus groups with people with different disabilities and health conditions and 1 focus group with employment support service providers and advisors
What are the issues and barriers to employment faced by those with disabilities or health conditions?	Qualitative – 5 participatory focus groups with people with different disabilities and health conditions and 1 focus group with employment support service providers
What key recommendations could LBI take forward?	Analysis of findings from quantitative and qualitative data

2.2 Ethics and Safeguarding

Ethical approval is the first step in all research that involves primary data collection from human participants. For each of the three research projects discussed below, ethics approval was sought and agreed following London Metropolitan University's research ethics guidelines. For the NYT research project with young learning-disabled people, research team members involved in visiting participating schools and in running the co-design workshops with young learning-disabled people had Enhanced DBS checks and certificates. All team members also attended a one-day Diversity and Inclusion training event.

2.3 Research Methodology

The research used mixed methods which included the following:

- Quantitative data collection and analysis to identify levels of unemployment among people with disabilities and to identify whether people with particular disabilities experience higher levels of unemployment. This included data from the Office of National Statistics (ONS), the Department for Work and Pensions (DWP), the National Health Service (NHS) and data provided by the London Borough of Islington.

A key point underpinning the research was that 'disability' is an umbrella term and that people with different disabilities and health conditions have different experiences and needs. Local level data allowed us to identify which groups experience the highest level of unemployment and then to carry out focus group interviews with them. ONS and DWP data are typically at a high level of granularity. To obtain a more detailed understanding of disabled subgroups, local Islington data was used to identify subgroups experiencing the highest levels of unemployment. The data identifies people with mental health problems, with long-term physical health conditions, with neurodiverse conditions, sight and hearing impairment and learning disabilities as experiencing the highest levels of unemployment both in Islington and in Haringey.

- Qualitative participatory research including a series of focus groups with people with different disabilities experiencing the highest levels of unemployment, to investigate the barriers to employment they experience.

Six focus groups were held overall, one with providers of employment support services in the Borough and five with residents with different disabilities (people with learning disabilities, people with mental health problems and neurodiverse conditions, people with long-term physical disabilities, people with visual impairments, and deaf people). The purpose of the focus groups was to explore disabled peoples' lived experience of the barriers they experience both in accessing work and in employment. The focus groups took place in several different locations, two in local centres providing services for learning disabled people and people with mental health conditions. Contact was made with disabled participants by Council officers on the research team who had a history of outreach work with disabled

residents and organisations particularly in relation to employment support services. BSL interpreters attended the focus groups alongside members of the research team from both the University and London Borough of Islington. Regular weekly team meetings were held online throughout the research process.

Feedback session – the findings were reported back to participants for further discussion in a feedback session and participants invited to be further involved in the Council's Equalities work. This is a good example of how participatory research can be transformative and empowering.

2.4 Key Research Findings - Islington Disability Employment Project

Key findings from the quantitative data showed that:

- 15% (32,515) of people in Islington have a disability or long-term health condition.
- 51% (13,610) of people with a disability in Islington are out of work
- the employment rate for people with a disability in Islington is 49% as compared with 80% for non-disabled people.
- mental health is the single largest health condition accounting for 28% of people with disabilities and long-term health conditions who are not in work, closely followed by people with long-term health conditions (26%), people with physical impairments (26%), people with neurodiverse conditions (11%), people with sensory impairment (4%) and people with learning disabilities (3%).
- whilst there is a spread of education qualifications amongst unemployed people with disabilities in the Borough, a high proportion have low-level qualifications.
- mirroring national trends, people with disabilities who are in employment in Islington are heavily concentrated in low-skilled and often part-time jobs.

2.5 Disabled People's Lived Experience of Accessing Work in Islington

Findings from the participatory focus groups with disabled people highlighted the following key barriers to accessing work:

- Discrimination and a lack of awareness, training and support from employers.
- Lack of opportunities in deaf-aware and disability-aware work environments.
- Recruitment methods.
- Digital literacy and exclusion.
- History of low skilled and low paid employment.
- Lack of confidence and low expectations.
- Low level of educational qualifications and negative experiences of education.
- Complexity of the benefits system.

- Lack of BSL support, disability awareness and support in services.
- Length and cost of diagnosis for neurodiverse conditions.
- Cost of living and lack of access to gym and/or swimming facilities for rehabilitation.

In the focus groups, disabled people highlighted that the key barrier to accessing work was unfair treatment, discrimination and a lack of employer awareness, training and support.

‘it's just basic awareness of what a deaf person needs to be able to communicate, really. Like fire alarms, pagers, writing things down, texting, It's not that difficult. It's that level, when we're talking about awareness, it's just basic stuff that people just don't get, it's not expensive’, (Deaf participant).

Stigma, stereotyping and ignorance were highlighted by participants time and again:

‘It doesn't matter how much positivity there is in the media about mental health, day to day there is still a lot of stigma and actual ignorance about mental health, especially from employers. The sort of things we come up against, ‘how dangerous is this individual?’ So, for us, stigma continues to be a massive barrier’, (Employment support service worker participant).

Deaf participants experienced discrimination extensively both in the workplace and in applying for jobs and highlighted the need for deaf awareness including simple ‘reasonable adjustments’ such as fire alarms for deaf people as well as the need to challenge the endemic and harmful stereotyping of deaf people's abilities:

‘Where do I start? Okay, a couple of months ago I thought I will go back to work and try and find a job. I went to the Jobcentre, and I was offered a couple of interviews; didn't get those jobs. It was in a school, and I just sensed that they were like, "Oh my goodness, how are we going to have a deaf person working in our school?", I felt a sense of panic and uncertainty. I could just see it on their faces’, (Deaf participant).

Indeed, for many disabled people, the recruitment process itself can be a major and early barrier to accessing jobs.

Disabled participants also highlighted their experience of having access at best to low-skilled and low-paid employment which resulted both in poverty and feelings of low self-esteem. Many participants had low expectations about the possibility of finding a job at all let alone a well-paid job.

‘I studied at a London Met. I got my degree from there. I studied pharmaceuticals, but that's of no use now because I've got no sight. No one is going to take me on. So, from then, I've done a lot of menial jobs like hospitality and security work and this kind of stuff. If I go to a job interview, and I tell them, I'm visually impaired, you won't get the job. I've been sent out of interviews, as soon as I've mentioned, visually impaired, "sorry we can't take you on". So, I had employment for two years doing basic cleaning’ – now I've got a 15-hour job with a charity, plus with jobs

there's 1,000 people applying for any job. Why would they take a visually impaired person?', (Visually impaired participant).

Disabled participants also spoke of the lack of disability awareness and support among employment services particularly at Job Centres. The presence of disability aware and BSL trained staff was of major importance to disabled people. The complexity of the benefits system was also highlighted as a barrier to accessing employment.

3. Haringey Employment Gap Project

3.1 Aims of the Research

Haringey commissioned the London Met Lab to conduct the Haringey Employment Gap research project in 2023-2024, as part of the Borough's Opportunity Haringey Inclusive Economy Strategy. The aim of the project was to identify those groups in Haringey who suffer the highest levels of unemployment and to highlight the barriers they face in accessing jobs. Evidence shows that Black, Asian and minority ethnic residents, people with disabilities, young people and lone parents experience higher levels of unemployment and the aim of this research project was to identify which groups are most affected and what the main barriers are in accessing work. The research project looked at how well existing employment advisory services in Haringey support Black, Asian and minority ethnic residents, disabled residents, lone parents and young people to get into work. In this project, the focus on disabled people was therefore one part of a wider research project. The focus on disabled people in the Haringey Employment Gap Project reflected the fact that 40% of disabled people in Haringey are not in employment.

3.2 Research Methodology

The Haringey Employment Gap research used mixed methods including:

- Quantitative data analysis (ONS, DWP and Haringey Borough data sets – including LIFT (Low Income Family Tracker of council's own administrative systems) and,
- Qualitative data collection and analysis – including 3 focus groups with people with mental health and neurodiverse conditions and people with learning disabilities to get a more detailed understanding of the barriers disabled people experience in accessing employment.

3.3 Recommendation - Impact of the Research on the Employment Gap Experienced by Disabled People

Based on the lived experience of disabled participants, recommendations were made to Islington and Haringey Councils which included:

- disability awareness training with local employers,
- working with partner organisations to target employment support and related services to people with disabilities,
- an outreach approach to employment support services which targets people with disabilities,
- wrap-around, holistic services for people with disabilities based on a case-working model of service delivery,
- co-location and outreach provision of related services, including Adult Community Learning, benefits and income maximisation and other services,
- British Sign Language (BSL) support.

3.4 Dissemination of Research Findings and Recommendations and Impact Monitoring

Monitoring impact has been a key part of the research projects and regular contact is maintained with partners who commissioned the research to update on impact. Some key impacts of the research to date include:

- Both Islington and Haringey have used the research on disabled people to help target council services and to focus on outreach as well as to tailor and adapt brokerage services,
- Islington Council identified a key problem in progressing the research recommendations was the lack of BSL trained interpreters locally and has developed initiatives to address the shortage including through piloting an apprenticeship scheme,
- Developing a neurodiverse toolkit for employers (led by the LIFT programme),
- Islington is also working with employers on the recruitment of residents with a global learning disability including exploring how to share best practice.

The research results have also been disseminated at local events: including at the International Day of Disabilities event focused on accessibility and inclusion for disabled people run jointly with London Met University, Arsenal, Google and Microlink in December 2024.

4. National Youth Theatre (NYT) Local Inclusivity Networks (Assemble) Project

4.1 Context

The NYT in collaboration with National Youth Arts Wales (NYAW) and Gig Buddies, secured National Lottery Funding to run the Local Inclusivity Networks programme, operationally known as Assemble. The aim of Assemble was to promote collaboration between disabled and non-disabled communities, reduce social isolation, and build grassroots inclusivity networks to provide community-based opportunities for young learning-disabled people. The Assemble project involved working with young learning-disabled children in nine schools in London, Manchester and South Wales, combining regular fortnightly workshop sessions in school with cultural visits to theatres and galleries.

Young learning-disabled people tend to have fewer social contacts outside of family and school and little experience of attending cultural events and venues. Evidence consistently highlights the significant challenges disabled people face in terms of developing social interactions and accessing opportunities. This includes a lack of connection between disabled and non-disabled communities. For young disabled people, opportunities to socialise with non-disabled peers are limited. Four in ten parents report their disabled children and young people in their care rarely or never socialise with their non-disabled peers (Scope, n.d.). There are also significant disparities in access to activities outside of school for young learning-disabled people in England and Wales. It has, for example, been highlighted that 1 in 3 young people with learning disabilities spent less than an hour outside their homes on a typical Saturday (Mencap, n.d.). In part this reflects the difficulties in accessing cultural venues and activities for disabled and young learning-disabled people. Recent research conducted by Leary and Ferri (2023) highlights the many barriers disabled people experience in accessing cultural activities.

NYT commissioned CARES to work in partnership with NYT and NYAW to conduct a research and evaluation project of the Assemble programme over the period 2023-2025.

4.2 Aims of the NYT Project

The table below highlights the five key research questions in the NYT evaluation project, which were grouped into three ‘work packages’

<p>WP 1 - Understanding the context of young disabled peoples’ engagement with the local cultural offer</p>	<p>WP 2 - Developing Inclusive Standards based on Young-Disabled People’s Lived Experience</p>	<p>WP 3 - Affecting Policy Impact</p>
<p>Research Question 1: What is the policy and local governance landscape within which the local inclusivity networks will be established?</p>	<p>Research Question 2: What constitutes a good and excellent end-to-end cultural experience for young disabled people and their support network?</p> <p>Research Question 3: To what extent can DYP voices influence future developments in policy? How have the co-designed</p>	<p>Research Question 4: How can the local offer, in terms of inclusivity and cultural opportunities, be enhanced through the work of the regional steering groups set up by the NYT?</p> <p>Research Question 5: To what extent can policy makers, parents, schools, and community partners access up-to-date information about the inclusive cultural offer and its consumption and how can better information dissemination contribute to the success of the initiative?</p>

4.3 Methodology

The NYT research and evaluation project was designed as a participatory research project. The project included a mixed method approach, including both quantitative and qualitative methods. The qualitative research included participatory and co-design research methods. The methods used are shown below:

Research Question	Methodology
1. What is the policy and local governance landscape within which the local inclusivity networks will be established?	Mapping of local policy and governance landscape. Focus Groups with local policy and governance organisations
2. What constitutes a good and excellent end-to-end cultural experience for young disabled people and their support network?	Co-design workshops with disabled young people (DYP) in the 3 locations Reflective Practitioner Workshops (termly) with project coordinators for each of the 3 locations Focus Groups with cultural venues and organisations in each of 3 locations Focus groups with disability organisations
3. To what extent can DYP voices influence future developments in policy? How have the co-designed inclusive standards been developed, disseminated and applied at the community level?	As above (Qu 1 and 2).
4. How can the local offer, in terms of inclusivity and cultural opportunities, be enhanced through the work of the steering groups set up by NYT?	Mapping of local offer Production of Kumu community maps As above (Qu 1 and 2) Observation of and participation in Steering Group meetings.
5. To what extent can policy makers, parents, schools, and community partners access up-to-date information about the inclusive cultural offer and its consumption and how can better information dissemination contribute to the success of the initiative?	Mapping of local offer Production and dissemination of Kumu community mapping of local offer Quantitative data – collection and analysis of disability data from ONS Census Production and dissemination of Disability Dashboard – based on quantitative data collection from ONS Census.

4.4 Key Findings of the NYT Assemble Project with Young Learning-Disabled People

The NYT Assemble programme had a positive impact on the young learning-disabled participants:

‘The most significant finding of our evaluation is that the Assemble programme delivered a transformative and empowering experience for young disabled people through its creative workshops, cultural visits, and co-produced performances. Our evidence suggests that the programme led to increased confidence, greater sense of belonging and more quality interactions with their peers for young disabled people, and to greater engagement with cultural and artistic activities. Overall, this demonstrates the programme’s unique value in promoting young disabled people’s inclusion and voice in the arts and cultural sector’, (Lewis et al., 2025).

Some of the key outcomes from the Assemble programme included:

- Personal growth of the young learning-disabled participants including growing confidence, communication and new friendships
- New and positive experiences from the cultural visits for young disabled people
- The good practice that is being shared with local cultural institutions and within schools among teachers and with volunteers, - teachers identified that the Assemble practitioners introduced different and creative ways of working with the students.

The evaluation of the Assemble programme also highlighted challenges including those identified below:

- Issues with the flexibility of fitting in cultural visits within school hours and staffing constraints
- Parental anxiety around trips and especially evening trips to cultural venues.
- The challenge of getting parental engagement
- Difficulties in accessing cultural venues and events due to public transport problems and taxis being expensive
- Struggles with volunteer recruitment especially in the more rural areas.
- Accessibility challenges in some cultural venues and a lack of age and time appropriate performances

The mixed research methods used, including the co-design workshops with young disabled people, the reflective practitioner workshops with the Assemble project coordinators in each of the three locations and the focus groups with cultural organisations in each of the three locations also highlighted the many barriers young disabled people face in accessing cultural venues, events and activities. These are documented and discussed in detail in the final report (Lewis et al., 2025) and mirror findings in other recent research on the barriers disabled people meet in accessing culture. (Leary and Ferri, 2023)

Both positive outcomes and challenges have highlighted important ways forward building on the young learning-disabled people’s experience and highlighting

the many barriers young learning-disabled people face in accessing cultural activities and venues and the ways in which these can be changed going forward.

5. Methodologies Used in Researching Disabled Communities

Looking more widely at disability research highlights the different methodologies used. Some of these are highlighted below.

5.1 Methodological Literature Review

A review of the literature on disability research was conducted and shows a focus on empirical research (80% of the 360 articles) and a smaller number (20%) adopting a largely theoretical approach. The empirical studies were predominantly quantitative in terms of methods used especially in those studies comparing employment, unemployment and wage levels between disabled and non-disabled people. Almost one third use qualitative research methods and a small minority (3%) used mixed methods to triangulate data analysis, enrich the study, strengthen the results and achieve rigorous conclusions.

In terms of methods of data collection, the most common was the use of secondary data from national public surveys (32%) and databases (25%). Interviews were the next most common method, used in 13% of cases. Case studies, ethnographic studies, fictitious cases, or simulations were often used in qualitative studies with small sample sizes, on topics such as the stigmatisation of disabled people. As for the sample size, almost half of the quantitative studies had a size exceeding 400 while for the qualitative studies it was less than 100. Qualitative data analysis techniques were mostly analysis of meaning (18%), thematic analysis and grounded theory.

5.2 Qualitative Research

Qualitative research essentially seeks to represent and interact with people. Interviews and focus groups can provide results that enable the researcher to understand the nuances or context behind responses. Pretto (2017) highlights the pros and cons of qualitative methods (such as interviews, observation, focus group and autoethnography) in disability research.

5.3 Inclusive Research

The disability research literature highlights how disabled people, like other marginalised groups, have been colonised by researchers who “have probed, recollected, appropriated and ultimately exploited their lives in insensitive and offensive ways”. It is argued that such methods of disability research need to be “decolonised” in ways that do not contribute to the pathologisation, othering or individualisation of marginalised people (Goodley and Runswick-Cole, 2012).

5.4 Participatory Research

Advocates of participatory research emphasise the right of all people to be actively involved as researchers in matters affecting their lives. Such research may require inclusive research strategies, implemented and analysed by accessible tools. Inclusive Participatory Action Research (IPAR), combining the approaches of Inclusive Research and Participatory Action Research, challenges traditional research relations where research is done on rather than by/with people labelled with, for example, learning disabilities. IPAR establishes more equitable power relations by involving those traditionally viewed as research subjects as co-researchers and ensuring the voice of people with disabilities must inform disability research design.

It is important to ensure disabled people participate in the research, not only as interviewees or subjects but also as consultants or co-producers. The Office for Disability Issues is committed to involving disabled people and their organisations at each stage of its work to achieve progress towards disability equality. (Farmer and Macleod, 2011). Their guide provides advice on how to involve disabled people throughout the research process and how to make fieldwork accessible to people with different types of impairment. It aims to help those responsible for research in government find the support and examples necessary to take research with disabled people forward, including finding ways for disabled people to say how and when they want to be involved." This guide advises on how to involve disabled people throughout the research process and how to make fieldwork and the report accessible to disabled people irrespective of their impairment. It is tailored especially for research in government but can be applied more widely. The book by Barton and Hayhoe (2023) on the other hand is a useful guide for early career researchers and highlights the similarities between participatory and emancipatory research approaches to data collection.

5.5 Emancipatory Research

Emancipatory research is a research perspective of producing knowledge that can be of benefit to disadvantaged people. It is an umbrella term that can include many streams of critical theory-based research including feminist, disability, race and gender critical theory.

It is often suggested that the emancipatory research paradigm serves as an ideal towards which researchers working within a social model of disability can aspire - its aim is to make disability research more relevant to the lives of disabled people. Above all, the 'emancipatory' research agenda warrants the transformation of the material and social relations of research production. In short, this means that disabled people and their organisations, rather than professional academics and researchers, should have control of the research process. This control should include both funding and the research agenda. Transforming the relations of research production so that control lies with disabled people and their organisations is, however, no easy task. For example, it is unlikely that disabled children would be able to control both research funding and its agenda. Hence many researchers committed to emancipatory ideals settle instead for doing participatory or action research.

5.6 Participatory Research - What we did

The methods used by LondonMet Lab in conducting the three disability research projects discussed in this Toolkit were participatory and adopted the Social Model of Disability.

5.6.1 Social Model of Disability

In the Islington and Haringey disability employment gap projects, the focus was on the barriers that disabled people experience in accessing employment and employment support services in recognition of the fact that it is inequalities in the labour market, in employer and employment services practices and in education and the discrimination against and stereotyping of disabled people that shapes their experience and can help explain the employment gap that exists between disabled and non-disabled people consistent with the Social Model of Disability.

This is not to deny the realities of having a disability or impairment and one of the aims of both projects was to go beyond the umbrella term of ‘people with disabilities’ and listen to the voices and experiences of people with different disabilities and health conditions. This highlighted both that disabled people face common problems but also that the causes of exclusion are socially constructed.

Similarly, the NYT Local Inclusivity Networks or Assemble project with young learning-disabled people adopts a Social Model of Disability in which the barriers faced by the young learning-disabled people in accessing cultural events and venues and in reducing loneliness and social isolation are seen as socially constructed and can be changed in ways which include rather than exclude young learning-disabled people.

Ethics approval and safeguarding – ethical approval was applied for and granted alongside Enhanced DBS checks and certificates.

5.6.2 Inclusive Training

For the NYT project, the team took part in one-day training session on Inclusive Practice led by the NYT project organiser, herself a disabled practitioner – this was a very important part of the research process.

5.6.3 Mixed Research Methods and Outputs

Each of the disability projects used mixed methods – including both quantitative and qualitative research methods. The methods were decided on jointly with partners commissioning the research.

Quantitative methods – collecting and analysing national and local data sets proved powerful in highlighting the scale of the employment gap and labour market inequalities between disabled and non-disabled people.

The Disability Dashboard (based on Census data) produced as part of the NYT project is a powerful tool giving wider access to data on disabled people and children.

The mapping of disability organisations, cultural venues and organisations and of the ‘local offer’ of services at local level available to young disabled people has also enabled us to produce a further powerful tool in the form of Kumu local community maps which provide an information tool available for young disabled people and their networks.

Alongside these quantitative methods, each of the projects has used qualitative and participatory research methods. The qualitative research methods used in the Islington and Haringey disability employment gap projects included a series of focus groups with people with different disabilities, impairments and health conditions – in each case this was led by an outreach member of staff from our partner organization who had close links with disability organisations and groups locally. The focus groups took place in different locations, with the focus groups with learning disabled people, and people with mental health and neurodiverse conditions taking place on the premises of local groups. In some cases, staff were involved in supporting participants and with the deaf focus group, two BSL interpreters were present throughout and at the feedback session at the end of the project. There were up to 12 participants in each group which were led by academic researchers. The focus groups were recorded and results circulated to participants prior to a follow up and feedback event towards the end of the project, also attended by staff from the Equalities team at Islington to encourage participants to continue working with them to improve the access of disabled people to Council services.

A wide range of qualitative research methods were used in the NYT Local Inclusivity Networks project including:

- regular reflective practitioner workshops with the teams in each of the three locations to reflect on the achievements and the challenges of the project,
- school visits to observe the sessions with young learning-disabled people,
- observing and contributing to Steering Group meetings in each of the three locations,
- co-design workshops in which young disabled-people could feed back their experiences of the project and of the cultural visits with the aim of gaining an understanding from young learning-disabled people themselves of what a good end-to-end cultural experience looks like for them,
- Focus groups with governance organisations, disability organisations and cultural venues and organisations,
- Interviews with key stakeholders and disability arts organisations
- Analysis of data collected from volunteers, teachers and participants from surveys, creative activities and informal conversations.

5.6.4 Impact

The outputs and impact of each of the three disability projects are a key part of the process – this involves ongoing dissemination of the research findings with local organisations and at local disability events in the case of the Islington project, ongoing updates on impact and on the NYT project playing a continued role in final project events and in taking the findings forward.

5.6.5 Lessons Learned

- Inclusive research practice – ensure team members attend inclusive research practice training provided by partner or respected local disability organisation.
- Ensure disabled people are involved in research design from the start.
- Agree clear and focused research aims, questions and methods.
- Work closely with local partners.
- Map local disability organisations and services - contact as many as feasible in terms of time and resources about the project – get their advice and feedback and any contacts.
- Follow up with local disability organisations and groups – set up interviews with contacts.
- Importance of outreach – work with local partner or contact who has good links with disabled organisations, groups and communities – to help set up focus groups and interviews.
- Quantitative research – map the data sources and data sets available and what each data set includes - identify gaps in data.
- Qualitative research – design research methods.
- Conduct interviews with key actors in local disability organisations, groups and communities.
- Ensure focus groups take place in local trusted spaces with relevant disability groups in the local community.
- Ensure preliminary results are shared with participants and feedback on findings, outcomes, and recommendations is facilitated.
- How can findings and outcomes be disseminated and impact ensured and monitored? What needs to be done, who needs to be involved, who will lead on this over what timescale.

5.6.6 Conclusion

The aim of the Toolkit is to help organisations and researchers who want to conduct research on and with disabled people.

In particular, the Toolkit aims to be of help to any organisation looking to improve the access disabled people have to employment or to services and cultural activities and venues.

Disability research can be a powerful tool in recording the voices and experiences of disabled people, in facilitating social change and in increasing awareness of the barriers disabled people face in accessing employment, culture and services.

This toolkit is innovative in that it is based on and showcases a number of research projects with people with disabilities conducted by LondonMet Lab and CARES with local partners across a range of different topics including access to employment and to cultural activities using participatory research methods and the Social Model of Disability.

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