Royal Statistical Society & Centre for Public Data
Roundtable on Poverty and Disability

December 2025

Contents

Background

The Royal Statistical Society (RSS) and Centre for Public Data (CfPD) recently convened a roundtable of experts in the disability policy, advocacy, and research space in the UK to discuss data gaps relating to the UK's data at the intersection of poverty and disability. This conversation is feeding into our research into poverty data gaps and how to address them.

This roundtable was the third in a series of meetings held as part of our poverty data gaps research, funded by the Joseph Rowntree Foundation's (JRF) Insight Infrastructure team. This project seeks to put forward practical, achievable, user-led recommendations for where the system can focus its efforts while being mindful of present constraints.

Within this project, we hope to seize on an opportunity to focus attention on the most important issues affecting researchers and organisations on the frontlines of alleviating poverty. It also serves as an information-gathering exercise for us, which will feed into workshops in early 2026 that will be more heavily focused on identifying and prioritising between various policy solutions, within and beyond the disability topic area.

This briefing summarises the main threads and themes coming out of our discussion. Rather than providing detail on everything discussed, we pull out the key points that were raised, taking account of both the breadth of opinion and the impact issues have had on attendees.

We would like to thank Maddy Rose and Owen Bowden, our colleagues at Mencap who were an invaluable help linking us to researchers working in this area.

Roundtable Objectives

The roundtable had 3 main objectives:

1. To identify specific data gaps that are affecting researchers and campaigners that work at the intersection of disability and poverty, broadly construed.
2. To sample views on the state of the UK's poverty statistics and how they might be improved.
3. To dive deeper into questions that had arisen during the first half of our research for this project, which will be summarised in an interim summary report soon after the publication of this write-up.

The primary questions that were discussed were:

1. What are the main questions relating to poverty and disability that you are trying to answer?
2. What would you like to be able to do with poverty and disability data, and is that feasible with current data?

3. What data sources do you rely on for answering your questions / supporting your work? Are they adequate for your needs?
4. What are the main gaps or challenges you've encountered when trying to answer your questions / use those data sources?
5. How could the UK's data relating to poverty and/or disability improve?
6. How can the UK's stats producers better support you in your work?

Key Themes

Disability data in the UK suffer from a variety of issues, including:

- Problems of inclusion in data collection and use;
- Insufficient detail about disabilities and poor granularity of geographical information about people with disabilities;
- Poorly developed methodologies around accounting for the additional costs of disability;
- Inaccessible data and a lack of transparent, open dialogue or infrastructure around acquiring and using data;
- Inconsistent standards regarding how disability data are collected and reported.

We heard many ideas for how the above issues could be addressed. A sampling of these includes:

- Open up data access by allowing more disaggregated data to be made available on Stat-Xplore and, where possible, making higher-quality data available for organisations to do their own analysis.
- Make publication of more detailed disability-related information standard, especially where this relates to economic, financial, and health outcomes.
- Publish local-area statistics for disability modelled after the successful Children in Low-Income Families (CiLIF) local-area statistics.
- Re-introduce a disability-focused survey at the national level modelled after the discontinued Life Opportunities Survey to collect much more detailed and comprehensive information about the prevalence of disabilities and the experiences of people with disabilities.

- Safeguard the quality of surveys and administrative data sources by making data collection and communication materials more accessible to would-be survey participants and service users.
- Facilitate comparison between UK nations by applying a consistent, harmonised approach to disability data collection across the Censuses in 2031.
- Develop a long-term data infrastructure strategy that prioritises data sharing between government departments as well as with external organisations and researchers.

Overview of Discussion

Organisations that attended the roundtable mentioned many different data sources that they rely on for supporting their work. These ranged from large, national, household surveys like the Family Resources Survey (FRS), Understanding Society, and the Census to more targeted surveys such as the My MS, My Needs survey or the Adult Psychiatric Morbidity Survey. Administrative datasets are also used frequently, especially where this relates to healthcare access and outcomes or benefits data.

Many of the issues that were discussed at our roundtable were general, pertaining to the UK's statistics relating to poverty as an overall body of information. Some were specific issues that affect particular sources. Here, we've grouped the main issues by broad theme.

Issues in Data Collection

We heard from participants that there were several key data gaps that affect data collection. One is that some people who may be the target of disability questions do not see themselves as disabled and therefore do not respond as survey designers may expect.

There is also an important issue around inclusivity in some large-scale surveys caused by an absence of accessible materials for disabled and deaf communities. This issue poses particular risk for data quality, since samples that inadvertently exclude segments of the population for this reason may lose representativeness.

Crucially, data gaps around who has accessibility needs create practical risks for those people because of the way that benefits sanctions are administered. One participant said that many of the people they support complained that DWP did not account for their communication needs when providing information about possible sanctions and how to avoid them. They said that this lack of consideration of accessibility unfairly led to sanctions or missed uptake of benefits.

Another significant data collection gap is that household surveys often exclude people in social care settings, which may have particularly problematic consequences for disability-related research.

Even when these specific gaps are avoided, there is a more general issue that some participants raised, namely that disability data often focuses merely on impairment and not conditions. Although it was recognised that impairment data is very important, condition data is essential for identifying the reasons for certain impairments and tailoring interventions that are appropriate. For instance, impairment data alone cannot tell us whether an issue is caused by a learning disability or mental illness, and the solution will likely depend on which factor is present—or on whether both are.

Granularity Issues

Related to the need for conditions in addition to impairments, participants raised a variety of data gaps that relate to the lack of adequate granularity within available data.

Organisations at the roundtable frequently expressed interest in having information about multiple aspects of wellbeing of people with disabilities. In addition to other areas, this included data relating to:

- Personal and household income;
- The number of people who are eligible for but not receiving benefits;
- Long-run employment and health outcomes;
- Benefits sanctions and how these affect individuals;
- Quantifying the additional costs associated with disability;
- Access to services and benefits for people with disabilities who are in poverty;
- Which groups of disabled people are affected most by deep poverty;
- Factors leading people into and out of poverty;
- How all of the above issues vary by demographic and social characteristics.

For some of these areas, current data do not enable robust answers, especially where there is a desire for intersectional or longitudinal analysis. Unfortunately, even where an answer is possible in principle, data in most of these topic areas is only available at highly aggregated levels of analysis, both by geography and type of disability.

Most participants noted that it is hard to get data for the communities that they are interested in, partially because data lack detail about the disabilities, often asking only if someone has a high-level or unspecified condition or illness (as in the English and Welsh Census). Unfortunately, most major surveys do not capture the variety of disabilities that people experience, nor do they capture robust information about how people are affected by them.

For many participants, this creates specific problems for their work. For example, although the English and Welsh Census allows respondents to identify if they use BSL (in an imperfect way), it does not allow for identification of how many of those people are themselves hearing impaired, let alone having more specific conditions or impairments.

Granularity issues like this frustrate even relatively basic research, such as getting the number of people experiencing certain impairments or conditions. Naturally, more complex questions about, for example, long-run employment outcomes can become exceedingly challenging to answer without compromising on specificity.

One specific, granularity-related issue that came up multiple times during our discussion was that age-related impairments cannot generally be separated from those that affect people acutely across the age spectrum. This makes it hard to know exactly what data are telling you, even when you know a little bit about the impairment itself.

In some cases, organisations rely on proxies, such as using Disability Living Allowance (DLA) claims to estimate the number of disabled children in local areas. Of course, this is only a partial fix since not all families will take up benefits for which they are eligible. Indeed, some participants mentioned wanting to be able to estimate the number of people who are eligible for disability benefits but are not in receipt of them. The current data landscape makes it challenging to answer such questions.

Some researchers have tried to answer questions relating to health outcomes and access for disabled people in local areas, and whether these vary by deprivation levels as measured by the Index of Multiple Deprivation (IMD)[1]. This requires gaining access to datasets that are not necessarily public (like hospital admittances), which creates friction in the research process. Reliance on this data also entails some concerns about data quality and reporting standards, since these may vary across hospitals and health jurisdictions.

Also related to local-area analysis, some participants noted that the recent development of the Children in Low-Income Families (CiLIF) local area statistics has proven useful in the child-poverty domain. They suggested that similar statistics that follow similar modelling approaches would be desirable for disability as well.

Another important contribution was about the Life Opportunities Survey, which is a discontinued survey dedicated specifically to disability-related topics. Participants noted that it used to be a great source of rich data about people with disabilities. They said that it captured relatively granular detail about conditions and impairments and the broader experiences of people with disabilities.

It was suggested that a reinstatement of a disability-focused survey would be a significant improvement for disability data and understanding more about poverty as experienced by people with disabilities.

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[1] Moreover, as IMD is an area rather than individual or household measure, it may be less helpful in some ways than longitudinal, individual measures from other, less easily accessed data sources. Additionally, in health datasets the given addresses are often for hospitals rather than patients, meaning the deprivation quintiles may not accurately correspond to the individuals of interest.

Costs of Disability

Several participants said they wanted to better quantify the costs associated with disability. Official statistics currently only manage to deduct the value of disability benefits from income[2]. This is an imperfect approach for at least the following well-known reasons:

- Not all people with disabilities receive benefits related to them.
- Disability benefits do not necessarily track the actual costs of disability.

Unfortunately, there is not yet a definitive and fully robust alternative approach. Although charities like Scope have created estimates of the average costs of disability, this only goes so far to addressing the problem given the diversity of experiences even among people who have the same overarching condition. Additionally, headline figures around costs don't communicate what disabled people go without—although there is again not an agreed way of accounting for this. Some participants called for the UK's stats producers to conduct an original piece of participatory research to help address this data gap.

Nevertheless, accurately estimating the costs of disability is important not just for knowing how many people experience hardship because of them, but also because it has clear ramifications for evaluating public policies that seek to support those with disabilities.

Issues in Data Access

Participants highlighted that some data that they want are available on Stat-Xplore, such as aggregated data from the Family Resources Survey (FRS). However, data available in that way cannot be broken down by condition. Presumably this is because of small sample sizes within year, but it was suggested that multi-year averaging could be used as a way of getting around that problem. In general, increasing the availability of disaggregated data on platforms like Stat-Xplore, even if limited, would be seen as positive.

Theoretically, more sensitive and detailed breakdowns could be derivable if analysts can access safe-room versions of the data, likely held on the ONS's Secure Research Service (SRS). However, because of the extensive security protocols involved with accessing data in the SRS, the timescales are often problematic for third-sector research, which needs to be more timely and policy-relevant than most academic research.

Moreover, not all third-sector organisations will necessarily have the in-house expertise or academic credentials to complete a successful application. Neither of these issues are unique to the disability research space.

Relatedly, there is sometimes a belief among statistics producers that third-sector organisations primarily benefit from ready-made analytical outputs that summarise key findings from raw data, rather than benefitting

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[2] This is true for Below Average Resources, which follows the Social Metrics Commission's guidance on this point. However, other official statistics like Households Below Average Incomes (HBAI) do not take this step, effectively

from access to the data themselves. This is based in the view that many organisations would not be able to make use of the data themselves.

Although this is true of some organisations, participants at our roundtable indicated that they would generally like both of the following:

1) Easily digestible and curated analytical outputs from statistics producers like DWP and ONS, giving high-level insights into their data.

2) Access to the detailed data so that they can do their own exploration and validation.

It should therefore not be assumed that direct data access is only of interest to academic researchers. Stats producers should consider ways to shorten the timescales for gaining access to secure data so that a more diverse set of users can make use of it. Where there are hard limitations on disclosure or security that prevent this, they should invest in publishing more of their own analyses that can dig into greater levels of detail on issues of interest to would-be data users.

Finally, some organisations find it necessary to rely on Freedom of Information (FOI) requests to access certain data. However, these are liable to be rejected or delayed, and some participants mentioned that the reasons for these decisions are not always transparent. Organisations sometimes resort to submitting Parliamentary Questions (PQs) via their MPs, which can generate more timely and forthcoming responses.

Of course, these workarounds are only an inadequate substitute for a culture and infrastructure of more open and collaborative access to data. Indeed, the administrative burden of fielding FOIs and PQs could better allocated to broader and more proactive publication of data by government departments.

Standardisation and Harmonisation

Issues around the standardisation and comparability of datasets across the UK came up a few times. Although in some cases the problem is partially one of data access—since it is cumbersome to collate data from across many jurisdictions—a lack of standardisation is also an issue per se, because it frustrates policy design, targeting, and evaluation.

In particular, participants emphasised the need for harmonised definitions and data collection methods across the four UK nations. They noted current difficulties in comparing statistics such as IMD and health data due to divergent methodologies across borders. There are planned harmonisations happening for IMD in the near future that should partially alleviate this issue.

A specific ask was for there to be harmony between the UK nations in the next round of Censuses with respect to the inclusion and wording of disability questions about impairments and conditions. The Government Statistical Service is already working on updating their disability harmonised standards, and it would be good if these were applied across the UK nations. However, as discussed above, wherever possible it would be ideal for this data to also allow for granular breakdowns of that information.

Participants also described significant variation in local authority data collection and quality, with some authorities lacking the capacity or interest to maintain accurate statistics about their population with disabilities. The result is that healthcare settings are often more reliable sources of information, although their data are also subject to variations in quality or accessibility, as noted above.

There was also some concern raised about the planned disestablishment of NHS England and what this would mean for data quality and standardisation going forward. Government will need to be careful to ensure that the comparability issues are not exacerbated by administrative juggling, especially where this relates to tracking and supporting the wellbeing of vulnerable people.

The Value of Better Data

It is important to reflect on the value that better data would have for organisations that are at the forefront of efforts to improve the lives of people with disabilities, and especially those that experience or are at risk of poverty and other forms of hardship.

Lots of third-sector organisations rely on data to inform decisions about where to allocate scarce resources for targeted service delivery. Better data—particularly more geographically granular and otherwise detailed data—would go a long way at facilitating smarter decisions in that space.

Additionally, the third sector plays a key role in the policy process, one that involves timely policy analysis and feedback to the public and directly to policymakers. Fulfilling that role requires meaningful and prompt access to high-quality data. If the UK can achieve a more open culture of data sharing, linkage, and access, then third-sector organisations will be better positioned to campaign for policies that can alleviate poverty.

Next Steps

We will soon be publishing an interim summary of our findings to date that synthesises information from across our research activities related to this project. In combination with that report, the findings from this roundtable will inform our priorities for the second phase of research, leading up to the project’s conclusion in the spring of 2026.

Early in the new year, we are planning to host a series of workshops aimed at bringing together expert data users and data owners to discuss priorities and feasible solutions within specific areas of focus where we feel we can make the most impact. Compared to the roundtable discussions held so far, these will be more oriented towards narrowing focus on one or two issues of central importance that might practically be addressable. More details will be made public soon.

If you would like to share details of your experience with poverty-related data gaps, please fill out our open call for input. You can also use that form to register your interest in taking part in other roundtables or interviews that we conduct as part of this project.