Royal Statistical Society & Centre for Public Data
Improving Disability Data Workshop

March 2026

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Background

The Royal Statistical Society (RSS) and Centre for Public Data (CfPD) hosted a workshop on February 19th, 2026 that brought together data users, producers, and systemic thinkers to discuss how to improve the UK's disability data. This workshop was part of our ongoing research into poverty data gaps in the UK, funded by the Joseph Rowntree Foundation Insight Infrastructure team.

In January, we published an interim report that highlighted specific and systemic gaps affecting poverty research, drawing on desk research, interviews, and roundtables that formed the first phase of our research. One of the specific topic areas we flagged as in need of improvement in that report was disability research, which appears to lag behind other areas in terms of its data quality and detail.

This write-up synthesises the various contributions made by attendees, who represented diverse charities and academics as well as representatives from statistics producers. We present challenges that were discussed situated alongside some discussion of ideas for solutions that were brought up during the workshop that have potential to help overcome them.

Challenges

Participants identified a wide range of challenges relating to the availability, quality, accessibility, and interpretation of disability data in the UK. While the specific issues raised varied across policy areas and research contexts, several common themes emerged during the discussion. Broadly, these are summarised here as conceptual and measurement challenges, inclusion and methodological challenges, and a set of specific gaps raised in the conversation.

Conceptual and Measurement Challenges

A recurring theme throughout the discussion was the difficulty of defining and measuring disability consistently. There are a variety of models for conceptualising disability, and some people perceived a tension between user requirements based on the social model (about people's exclusion from society) and those based on the medical model (about people's health conditions/impairments). The choice of model can have significant implications for how sets of disability questions are designed, and participants at the workshop raised at least two sets of challenges.

Firstly, there is a challenge around inconsistency and misinterpretation. Several contributions made on the day made reference to the fact that "terminology / definitions [are] inconsistent, [and] not well understood." Others pointed to the absence of a standardised approach to recording disability across different datasets. This means datasets often have discrepancies that frustrate analytical work that needs to make use of multiple data sources.

Secondly, there were concerns about the trustworthiness of disability measures, particularly the Government's standard definition of disability (which is based on people saying that their health condition/disability limits their usual daily activities). The difficulty here is that this measure will not be reported consistently – for example, if disability inclusion improves, then on this definition, fewer people will report a disability.

Therefore, coming to a more consistent measurement framework would be welcome by disability researchers. At the same time, changes away from current measurement approaches can introduce discontinuities into existing time series, so any benefits of development work have to be balanced against importance of maintaining consistency.

Inclusion and Methodological Challenges

Participants also raised concerns about whether disabled people are adequately represented in existing datasets. Several comments highlighted barriers that can prevent some groups from participating in surveys or other forms of data collection.

Accessibility challenges were a particular focus. For example, one participant noted the importance of "accessibility for deaf sign language users," while another emphasised the need for "multiple step[s] for inclusion – [including] culture and linguistic comprehension." These comments point to the fact that standard survey approaches may not always be accessible to people with different communication needs.

On the other side of the coin, more inclusive survey formats and methodologies are not free to implement. It was noted that survey agencies commissioned by government departments already struggle to maintain a large pool of experienced field workers. These constraints are likely to be all the more binding when specialist skillsets are required to include disabled communities. Additionally, "unrealistic requirements" were seen by some producers as a challenge that users did not always understand well. In particular, some comments pointed to the fact that even representative surveys may struggle to get sample sizes for specific disabled communities that are large enough to meaningfully analyse separately. These points highlight the practical limitations that must be considered when trying to craft solutions.

Despite these practical limitations, there are principled reasons for wanting inclusive surveys. Even if a community is small, we should still make efforts to ensure its voices are represented in surveys, especially when the data might get used to make decisions about them. It is also good practice to embed inclusivity in our institutions wherever possible.

Inclusivity in our discussion also went beyond considerations of survey design. Several attendees remarked that gaps in charity skills and capacity for using data were problems for them. Relatedly, they did not always know which datasets to use to answer their questions—a discoverability issue that we discussed in greater detail in a separate workshop on improving data access for civil society. Still other users from the charity sector pointed out that although academic papers could provide valuable lessons for their frontline work without requiring them to engage in hands-on data analysis, they are generally hard to parse and written for academic audiences, which limits their practical value for these users.

Specific Data Gaps

Attendees discussed the ways in which existing poverty statistics fail to capture economic realities faced by disabled people. A common observation was that the additional costs of disability are impossible to accurately account for in official data sources, and even coming to a clear definition of what an extra cost *is* might be challenging. This is a well-known issue that means disabled people may appear above the poverty threshold even when their effective disposable income would be significantly lower once disability-related expenses are taken into account.

Another issue is the "lack of data explaining [the] increase in disability prevalence in [the] working age population." This itself may be related to the conceptual and measurement issues discussed above, since the reasons behind someone

identifying as disabled may vary over time and relate to several factors, like changes in the health of the population and changing social views towards disability.

One frequently cited gap relates to social care. Participants noted a "lack of data on social care," particularly in relation to how access to services affects the financial and social outcomes of disabled individuals. Others pointed to a "lack of data on employers' disability equality practices." This latter point was supplemented by an observation that relevant information is seriously outdated—the last nationally representative dataset covering that subject was the Workplace Employment Relations Survey from 2011.

Potential Solutions

Improving the Measurement Framework

As mentioned in the Challenges section, there are ongoing debates about the right approach to collecting disability data. The range of possible positions was evident in some of the contributions we received throughout the day. For instance, several attendees at our workshop expressed a desire for the UK's data to follow what is known as the "social model" of disability, which emphasises the relationship between impairments and the surrounding social context. Other participants were clear in arguing that questions about functional impairment are important—one asked for a "functional measure of disability to complement the social model." Other contributions focused instead on a need for robust data on (medical) conditions.

Getting this right will be important for disability research in the future, but the aim of our workshop was not to discuss or resolve these debates specifically. Rather, attendees almost universally expressed a desire for practical progress here, realised through more extensive, representative, and detailed data collection to enable analysis using various models. There was agreement that any movement towards that objective would be a welcome improvement over the status quo.

At the same time, attendees' contributions emphasised the value of coherence, comparability, and consistency between datasets. Continued development of harmonised standards are therefore of prime importance. There is also clear desire for more concerted and facilitated efforts to be made towards coming to a definite framework for collecting disability data that fits those criteria. Key producers like ONS, DHSC, and DWP should play a central role here, but they should be sure to take a co-productive approach, as we discuss elsewhere in this write-up.

New Surveys and Other Initiatives

One idea we discussed at some length was the possibility of running a new, dedicated survey for disabilities on a regular basis. The potential benefits are significant, including:

- Allowing space for more questions aimed at identifying disabilities in detail, including both social barriers and functional impairments.
- Getting sample sizes large enough to meaningfully analyse the disabled population using the more detailed set of questions (assuming there was enough resource put into the survey to achieve this).

- Tracking issues that are relevant for the economic wellbeing of disabled people specifically, such as barriers to employment, discrimination in the workplace, costs associated with disability, etc.
- Capturing multiple interrelated aspects of disability and associated challenges in one data source, thereby enabling more complex analysis than is currently feasible outside of major linked data sources.

Of course, there are barriers to implementing this solution, including financing its substantial cost and the aforementioned sample size considerations. Others are perhaps more innate to a disability survey as such. For example, a survey that is advertised for disabled people specifically—using that terminology—might inadvertently lead certain groups (e.g. members of the deaf community) to not respond. A survey would need to be sensitive to this dynamic and involve well-considered communications to be as inclusive as possible.

Nevertheless, participants also discussed more modest, adjacent proposals. Some of the benefits of a disability-specific survey could be obtained by expanding what already exists in other surveys. Candidate surveys mentioned on the day were a module in the Health Survey for England funded by DHSC, or a follow-up survey from disabled people in the Family Resources Survey from DWP, or the Labour Force Survey run by the ONS. Even additional booster samples for disabled people without additional questions might be effective at allowing intersectional analyses of particular types of disabilities that are currently challenging with existing sample sizes.

Beyond a survey targeted at disabled people, workshop participants were also interested in getting a national dataset with information about employer behaviour with respect to disabilities. This could include capturing practices related to disability confident employer schemes, or requiring employers to report on disability pay and employment gaps.

Co-production

A clear and consistent desire throughout the workshop was a desire from users to be involved in co-production of disability data and statistics. Many of the challenges above may be partially overcome by ensuring that disabled people and charities that represent them are better involved in decisions.

For instance, those groups will have helpful insights about how to better deliver accessible surveys to people with specific disabilities. They would also be a core group to include in the process of coming to an agreed settlement about the right set of questions to ask in an updated standard for disability, or in the development of disability-related surveys and modules more generally.

One specific suggestion for a desirable co-productive forum was in a hypothetical scoping project to determine how to assess the additional costs of disability in a realistic way using official data sources, or alternatively, to find a feasible second-best solution for imputing such costs. This sort of project would necessarily require involvement of government departments, but would do well to include academics, third-sector researchers, and people with lived experience of a range of disabilities.

Indeed, it was clear from the conversation that, despite the significant issues with disability data at the moment, there is a lot of pragmatism within the user community about how to best move forward. There was broad willingness to collectively contribute to incremental but consistent improvements on achievable goals. To that end, establishing more permanent, cross-cutting infrastructure for co-production and user engagement to take place could be a big win.

Moreover, it will be important to manage expectations in any of these endeavours. Attendees remarked that the system needs to "be clear on what the promise is" and be careful to not "give people wrong sense of hope." Permanent forums for communication between producers and the disability data user community could go some way to achieving that objective, although they will require investment and commitment from multiple parties.

Improving Access to Data

Many of the contributions made on the day were fundamentally about improving access to and accessibility of existing data. This is a topic that we covered in greater detail at an earlier workshop, and many of the themes here were the same. Some notable suggestions at this disability data workshop included:

- More investment in data trainings aimed at charities specifically, taking account of their levels of technical expertise and the need to be affordable. They would also ideally be regular and well-advertised. ONS trainings on how to use Census data were noted by one participant as particularly useful.

- More charity-university partnerships for linking people on the frontlines of advocacy or those with lived experience to people with technical skills.

- Some users suggested having a more flexible and responsive way to get DWP data could be useful, specifically (but not exclusively) more granular data on poverty or hardship by health condition. Notably, some data of this kind is available on Stat-Xplore, and several attendees made positive comments about it as a "go-to" resource when first looking for data. But looking at additional models, some attendees pointed to arrangements run by the ONS where users can pay for the creation of bespoke tables from datasets that are not necessarily made public or made available via secure environments, which themselves tend to be inaccessible to charities.

Additionally, several attendees noted the need for better linkages between existing datasets that may be held across different government departments. Linked datasets (or aggregated statistics based on them) could be made available to researchers on public tools that may currently lack detail relating to disabled populations.

Adjacently, cutting-edge research often requires both the creation of these linked datasets—which can be a significant task in its own right—and initiatives to make their detailed versions available to researchers. There are already examples of major linkage projects being successful and now being accessible via specific routes (e.g. the Longitudinal Education Outcomes dataset). Linked datasets that include enough information about disability to be useful to researchers would also be welcome.

Next Steps and How to Get Involved

We are in the process of synthesising findings from across our various workstreams and will produce a set of targeted recommendations for fixing certain data gaps, which will be aimed at multiple stakeholder groups. The solutions that were proposed at this workshop will help inform those recommendations and our advocacy work going forward.

The work from this project is set to conclude at the end of March 2026. One of our last workstreams will develop case studies of specific data gaps and their consequences. Some of these will focus on issues discussed here. If you have specific data gaps that have affected you that you think we should be aware of, please email Dakota Langhals, RSS Policy Researcher, at d.langhals@rss.org.uk, or policy@rss.org.uk.

If you have encountered specific data gaps when using data related to poverty in your work, please consider contributing to our catalogue of data gaps as presented on our Poverty Data Gaps Explorer tool. The intention is for it to grow into a crowd-sourced catalogue of data gaps that can help organise and coordinate advocacy for the fixing of specific, data-related issues in poverty research.