

## NATIONAL STATISTICIAN'S INCLUSIVE DATA ADVISORY COMMITTEE

NSIDAC(22)08

### *Progress towards improving inclusivity of UK data and evidence on disability*

#### **Purpose**

1. This paper collates the latest picture of key initiatives across UK government, the Devolved Administrations, Office for National Statistics (ONS) and the UK Statistics Authority (UKSA) to improve inclusivity of UK data and evidence in relation to the lives of disabled people, taking forward the Inclusive Data Task Force (IDTF) recommendations.

#### **Recommendations**

2. Members of NSIDAC are invited to:
  - i. Comment on the progress made in improving inclusivity of data and evidence in relation to disabled people;
  - ii. Advise on priority areas for further progress;
  - iii. Advise on any areas where further collaboration across the UK statistical system would be beneficial; and
  - iv. Consider how NSIDAC members may wish to contribute to future work to improve disability data and evidence.

#### **Background**

3. The Inclusive Data Taskforce recommended improvements in data and evidence relating to disability in several areas. This included:
  - identifying disabled children and parents as priority groups in ensuring that all groups are robustly captured across key areas of life in the UK;
  - a call to transition measures of disability to approaches based on biopsychosocial conceptual frameworks of disability as part of ensuring appropriateness and clarity of concepts being measured, as covered under item 3 of the Agenda, paper NSIDAC(22)07;
  - reviewing income equivalisation methods to improve estimates of income and fuel poverty among disabled people;
  - use of a broader range of methods to enhance understanding of the experiences and enable inclusion of currently under-represented voices, including adults and children with disabilities; and
  - a call on ONS to actively engage in international initiatives to improve inclusivity of statistics, including a suggestion that ONS should seek the establishment of a UN City Group on Inclusive Statistics.
4. The following sections summarise initiatives in these and other areas across UK central government (Cabinet Office); the Devolved Administrations; and the UKSA and ONS.

#### **Discussion**

*Cabinet Office Disability Unit initiatives to improve disability data*

5. Following the publication of the National Disability Strategy in July 2021 Cabinet Office has developed a [Data Disability Improvement Plan](#) to improve the quality and relevance of government-held data on disability (IDTF recommendation 3.2 and 3.3). A bottom-up approach was piloted with 3 departments and was found to be administratively cumbersome and inefficient. A revised approach with a central team of analysts however was not taken further due to lack of funding in the Spending Review (SR) 2022-25 and delayed following the Judicial Review of the National Disability Strategy. Currently, recruitment is underway to continue the project on a zero-cost basis and work with UK Government Departments to improve existing disability related data.
6. Plans to develop and roll out a UK-wide survey in 2022/23 on the needs of, and barriers faced by, disabled people, have been delayed due to lack of funding in the SR 2022-25. However, the Cabinet Office remains committed to better understanding the experiences of disabled people in society and informing targeted policy-making across government and is seeking alternative sources of funding to take the survey forward (IDTF recommendation 3.5).
7. The Cabinet Office has also commissioned additional research and has worked with NatCen and the ONS to plug evidence gaps with regards to disabled people. Work with NatCen on attitudes towards disabled people on the workforce resulted in an additional module in the British Social Attitudes Survey. The data confirm the ongoing existence of disability-related prejudice which affects disabled people's work experiences. Work with ONS on accessibility of products and services has highlighted a number of issues that need to be addressed (IDTF recommendation 6.1). Cabinet Office Disability Unit analysts' systematic review of lived experience research in the UK over the last decade was concluded in March 2022, with the resulting database being used to explore policy-relevant topics in more depth.

### Work to improve disability data and evidence across the Devolved Administrations

#### *Northern Ireland*

8. The Department for Communities in Northern Ireland covers policy in relation to disability, Sexual Orientation (LGBTQI+), gender equality, and active ageing topics. In line with commitments made under 'New Decade, New Approach', the Executive agreed to the development of a suite of [Social Inclusion Strategies](#): Anti-Poverty; Disability; Gender Equality and LGBTQI+. Each area has a strategy in development at the moment. As part of the development of the disability strategy, analysts have been undertaking data-related work and improving access to data, which will inform the strategy or form part of the action plan associated with the strategy when launched.
9. Outside of the strategies, analysts have contributed to a [research report on disability in the NI labour market](#), published in August. Although the labour market research was a one-off piece, there are ongoing research programmes in the Department for Communities, with a number of projects on disability which may contribute towards the implementation of the IDTF recommendations on disability data.

#### *Scotland*

10. The Scottish Government's Equality Analysis Team lead on the [Equality Data Improvement Programme \(EDIP\)](#) a wide-ranging programme of work aimed at strengthening Scotland's equality evidence base. The EDIP project board is co-chaired by the Scottish Government's Chief Statistician and Chief Social Researcher - it has external membership from a number of key partner organisations. The EDIP has the buy-in of Ministers and analytical leaders across the Scottish Government, including its Analytical Leaders Group (ALG). Analytical Services Divisions have a strong role to play in the implementation of robust equality analysis.
11. The ALG approved the formation of a network of internal analysts to help take forward key elements of the programme. This network drove a comprehensive internal Equality Data Audit in late 2021 - this used a RAG analysis to show which official and national statistics datasets produced statistics broken down by each of the equality characteristics. Further to this, these lead analysts also produced draft improvement plans which formed the basis of an [external consultation](#) that ran between July and October 2022. This consultation, and findings from the supporting stakeholder engagement events held throughout September 2022, will form the basis of Scotland's next Equality Evidence Strategy.
12. Analysts from around the Scottish Government routinely include equality breakdowns in their analytical outputs and these help to populate the [Equality Evidence Finder](#) which presents analysis across the protected equality characteristics. This is a first point of call for policy makers to inform Equality Impact Assessments which ensure that policies and spending decisions do not have adverse impacts on particular groups. Analysts also provide equality breakdowns for National Performance Framework indicators. As part of the EDIP, the Scottish Government analysis team refreshed its [guidance notes around the collection of data](#) on disability collecting equality data in line with the ONS harmonised standard.

### *Wales*

13. In January 2022, the Welsh Government established the Equality, Race and Disability Evidence Units. The units will focus on improving equality evidence for use in decision making, provision of services, research and debate, and assessing, monitoring and evaluating policies, both within the Welsh public sector and beyond. An [overarching strategy](#), describing the scope, remit and intentions for the Units, was published in September 2022 alongside a list of priorities.
14. The Disability Disparity Evidence Unit is committed to developing a programme of work to improve the collection of data relating to disability, investigate long-standing problems using a combination of qualitative and quantitative research methods; and deliver innovative ways to address ongoing evidence needs relating to equalities and socio-economic disadvantage.
15. The Units' overarching strategy outlines a commitment to coproduce as much work as possible. Therefore, a programme of work is being undertaken to develop an approach to co-producing research and analysis. Internal and external stakeholders, particularly those with lived experience, have been involved to help shape and steer the initial stage of this work stream.

16. This approach to co-production is being tested with a pilot research project to better understand how to measure the social model of disability. A key recommendation of the [Locked Out: Liberating disabled people's lives and rights in Wales beyond COVID-19 report](#) was use of the social model of disability, which Welsh Government has in principle been committed to since 2002 and the commitment was reaffirmed by the Executive Committee in December 2019. It is anticipated that research will be commissioned in the first half of 2023. Other projects at the initial scoping stage include research into the impact of the cost of living crisis on disabled people as well as a review into barriers to employment faced by disabled and neurodivergent people.
17. The Disability Disparity Evidence Unit will also work closely with the [Disability Rights Taskforce](#), which has been established in Wales to look at the barriers faced by disabled people. The Minister-led Disability Rights Taskforce is taking forward the work to address the inequalities highlighted by the Locked Out report and oversee the development of actions that will form a Disability Rights Action Plan.

#### *Recent initiatives from ONS to improve data and evidence about disabled people*

18. ONS data and analysis are providing further insight into the lives of disabled people. This section describes new qualitative research exploring disabled people's experiences, administrative data linkage to provide new insights into outcomes for disabled people and the upcoming publication of Census 2021 findings for England and Wales, which includes intersectional analysis of disability.

#### *Qualitative research with disabled adults and young people*

19. ONS have undertaken two qualitative research projects with disabled people over the past year. One project focussed on disabled adults and their experiences of accessing and engaging with activities, goods and services, feeding into Cabinet Office Disability Unit's work in this area (including both a [survey](#) and [qualitative research](#)); and the second explored the [educational experiences of children with special educational needs and disabilities](#) (SEND), which is being used to expand the evidence base for the Department for Education's (DFE) consultation and review of SEND provision.
20. In keeping with the IDTF recommendations to engage with research participants throughout the research process, both projects involved consulting with those with lived experience, expert academics, policy colleagues, disability and children's civil society organisations and relevant regional stakeholder networks. These groups fed into the research design, data collection, analysis, reporting and dissemination of findings. Methods and materials for interviews with young participants were refined with feedback from a Youth Expert Panel of 13 young people with SEND aged 11 to 16 years attending a range of educational settings. Accessibility considerations for disabled adult participants were also refined with feedback from an 'experts by experience' advisory group of six disabled adults.
21. Both projects were the result of a collaborative effort, with technical support from academic experts throughout, with NSIDAC member Professor Tom Shakespeare and Professor Nicholas Watson (University of Glasgow, Chair of Disability Studies) providing ongoing advice and assistance on the disabled

adults' project. Professor Janice McLaughlin from Newcastle University provided guidance and support on the SEND project.

*Widening our dissemination to engage with affected communities*

22. Also in keeping with the IDTF recommendations to make the findings as accessible as possible to research participants, we have published online, both in our standard format and in easy-read versions for the disabled adults project and in a [young-person friendly version](#) for the SEND project. We also commissioned a video for the disabled adults project which is available on [Vimeo](#), to enable wider access, and we are currently commissioning a video for further dissemination of the findings from the young people with SEND study. Civil society organisations have also disseminated the findings through their networks.
23. Professor Tom Shakespeare has collaborated with ONS on a 'teach-in' to share the findings with the Cabinet Office Disability Unit, and he and Professor Nicholas Watson are also producing academic papers for publication. A separate teach-in with DFE colleagues on the findings of the project about young people with SEND has also recently been completed.

*Linked administrative data on outcomes for disabled people*

24. Linked data from ONS' Public Health Data Asset (PDHA), that draws together 2011 Census records, death registrations, primary care records, Hospital Episode Statistics (HES) and vaccination information have been used to investigate the elevated risk of death involving COVID-19 for disabled people, as well as those with specific vision and hearing impairments. To enable the latter, we published a working [paper assessing the strategies to produce more detailed insights into the variety of experience of disabled people with different impairments](#). Linkage to HES in particular has been key to these insights for people with a vision and hearing impairment. Linkage to HES in particular has been key to these insights for people with a vision and hearing impairment.
25. In addition, in collaboration with academia, we are investigating the impact of the pandemic on patterns of hospital admission for conditions linked to new-onset disability and will expand this research to look more specifically at the elevated risk of such conditions after a positive COVID-19 infection. Linked data offers further opportunities for research due to the resolution it provides on underlying factors that contribute to the disabled lived experience.
26. A further project being run jointly by ONS, Department for Work and Pensions, Department for Health and Social Care, and Cabinet Office is exploring the feasibility of creating and analysing a dataset which links personal and household characteristics to health and labour market outcomes in order to better understand the long-term health and employment outcomes due to COVID-19 on disproportionately impacted groups, including those with a disability.

*2021 Census analysis of disability*

27. Census 2021 data, planned for release in 2023, will shed new light on disabled people. First results of the number of disabled people in England and Wales are due to be published (provisionally) on 19 January. These will incorporate age standardised proportions of disabled people to compare how rates of disability

have changed since 2011 and compare across geographical areas of the two countries.

28. Following this, a programme of analysis will explore disability by deprivation and wider outcomes. We will be able to explore intersections between disability and other protected characteristics and address particular evidence gaps, such as disabled people living in communal establishments and disabled children. Beyond this, linkage of 2021 data to other sources of health data will provide further opportunities to add new and more granular insights into the lives of disabled people.

### United Nations City Group on Inclusive Data

29. Work has begun to explore the feasibility of establishing a new UN City Group (IDTF recommendation 2.6). In March 2023 the UK National Statistician Sir Ian Diamond will attend the 54<sup>th</sup> UN Statistical Commission where the UK will initiate conversations regarding the need for a City Group on inclusive data. In support of this the UKSA International Team have started informal discussions with colleagues in the United Nations Statistics Division, who have indicated they would support a new group.
30. We are working towards establishing the group in 2025. This will allow for the conclusion of the current Titchfield City Group on Age and Ageing, which ONS is responsible for convening, as well as engagement with international colleagues to establish the aims and objectives of the new group, ensuring we are addressing the needs and requirements of the international community.
31. In addition to this, the ONS is actively engaged with other international initiatives including: reporting to the [Washington Group on Disability Statistics](#); contributing to a [UN Economic Commission for Europe report](#) on statistics on children (including disabled children); working with the Cabinet Office to inform reports by the UN Committee on the Rights of Persons with disabilities for the UK, and being members of the World Health Organisation Functioning and Disability Reference group, which discusses and monitors updates to the International Classification of Functioning, Disability and Health framework.

### **Conclusion**

32. This paper has set out key initiatives to progress IDTF recommendations to improve inclusivity of data and evidence in relation to disabled people in the UK. It summarises work currently happening or in the pipeline in UK central government, the Devolved Administrations, and ONS/ UKSA. Committee members are asked to note and comment on the progress made; identify priority areas for further progress; suggest areas where further collaboration may be possible across the UK statistical system; and ways in which they might like to be involved in further work to improve UK data and evidence on disability.

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