

PPR's response to the government's <u>consultation</u> on Office of National Statistics Health and Social Care Statistical Outputs

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In this exercise the government is seeking feedback on its proposals to change its statistical outputs on health and social care. PPR's response is grounded in United Nations guidance on a <u>Human Rights Based Approach to Data</u> (2018), the key principles of which include data disaggregation, transparency and accountability amongst others. We also draw the government's attention to the recent work of ESCR-net, an international network of 280 non-governmental organisations, whose members recently developed <u>'Making Communities Count'</u> which recognises that 'official data collected by states and public authorities usually does not fully represent communities' needs' and sets out principles through which data collected can better reflect the experiences of rights holders including marginalised people.

PPR would consider the ONS' <u>aim</u> of strengthening the statistical picture of health and social care in the UK by creating greater statistical coherence across the four nations to be consonant with this human rights based approach. However the government's proposals in the consultation document seem to go in a different direction. Rather than improving comparability by raising the standard of data collection, analysis and publication to the highest level available across the four nations, the government's proposals amount largely to amalgamating data into fewer reports overall, published less frequently (in many cases, every two years rather than annually).

PPR are concerned that these proposed changes, if implemented, would ultimately make the ONS' 'big picture' less descriptive, less indicative of reality on the ground and less outcome-oriented, particularly around key issues like health inequalities and the challenges faced by people living with disabilities. Public access to data is a key component of the principle of transparency (HRBA to Data, pp. 14-15); reducing the frequency of data publication to, in many cases, every two years rather than annually would clearly run counter to this principle. This in turn would impact upon the principle that "data should be used to hold States and other actors to account on human rights issues" (HRBA to Data, p. 18).

Similarly, disaggregated data allow for comparison across population groups and, according to the UN, "can inform on the extent of possible inequality and discrimination" (<u>HRBA to</u> <u>Data</u>, p. 7). At a time when health and social care systems across the UK are increasingly under pressure -- and as people themselves continue to struggle to cope with the fallout

from the Covid pandemic, the cost of living crisis, climate change and related factors -more disaggregated data rather than less, allowing for greater scrutiny rather than less, is required. In this context it is difficult to understand the government's rationale for ceasing altogether, for instance, ONS recording of deaths amongst homeless people.

The availability of robust, disaggregated data is critical to understanding whether policy approaches, budgets and government intentions are creating rights based outcomes and this data should be available to the widest possible range of stakeholders including elected members of parliament/assemblies as well as academia and civil society.

Health inequalities

Health inequality data (including the annual NI Health Inequalities report, but also comparative data showing that Northern Ireland's <u>healthy life expectancy</u> averages and disability-free life expectancy averages are consistently at the low end of the scale across the UK) closely informs our rights-based work on housing, work and mental health, as do specific data sets (eg avoidable mortality statistics).

Here, the government proposes to reduce the number of discrete publications (in some cases by merging them), and to reduce their frequency to once every two years rather than annually. This amounts to a serious reduction in the level of scrutiny of health inequalities in our society at a time when the availability of information, and the scrutiny that it permits, is ever more vital.

Mental health

The body of statistics produced by the Department for Health and Social Care (DHSC) around mental health have historically been more robust and complete <u>than that available</u> <u>for Northern Ireland</u>, and have served as a useful benchmark here. (To give just one example, a <u>highly critical review</u> into mental health data in NI by the Office for Statistics Regulation (OSR) <u>found</u> that mental health statistics in NI were not serving the public good, by not enabling a range of statistics users to answer key important questions on a particular topic.)

The government's proposals in this consultation, however, do not appear to be aimed at improving Northern Ireland's statistics to the standard found elsewhere in the UK in order to achieve greater statistical coherence overall. Rather, the proposal is simply to 'consolidate and streamline' a range of mental health publications produced by the Department for Health and Social Care – including those on the mental health of children and young people, perinatal mental health and suicide prevention.

Given the numerous indicators of increasing incidence of mental ill health linked to the cost of living crisis, the aftermath of the Covid-19 pandemic and a range of other factors (including, in Northern Ireland, the ongoing impact of conflict-related trauma), this is deeply concerning. Our current conditions require more scrutiny and understanding of these issues, not less.

Disability, learning disability and autism

Social housing need in Northern Ireland is an important area of work for PPR. The ONS '<u>Outcomes for Disabled People</u>' data for the UK as a whole highlights the relatively high reliance amongst people living with disabilities on social housing. (Housing need amongst households including at least one person with a disability is a key component of overall social housing need here, and one we are working to address through our <u>Take Back the City</u> housing initiative in Belfast.)

PPR also works with people fighting to access their right to work and to social security. In July 2023, for instance, we <u>submitted</u> information to the UN Committee on the Rights of Persons with Disabilities inquiry into the impact of the changes to social security ('welfare reform') in the UK. The 'Outcomes for Disabled People' data – while it does not include information on benefits – does contain UK-wide data on employment, disaggregated by age and by type of disability. This provides essential grounds for comparison to help people understand the wider context of challenges facing people living with disability.

Mental health is another key area for PPR, with clear linkages to other campaign areas including the <u>right to a home</u> and to <u>income</u>. The 'employment rates of disabled people by main impairment' table in the ONS 'Outcomes for Disabled People' report includes the categories of 'mental illness or other nervous disorders' and 'depression, bad nerves or anxiety'. Our work here indicates that a change is required in the overall approach to mental health and mental ill health – while the ONS language may be problematic, it is nonetheless vital that the links the data sheds light on, between mental health and work, and the impact of mental ill health on people's ability to work, are made clear. The 'well-being' data in the ONS publication, which – like the 'loneliness' data, consistently shows across all indicators that the people with disabilities face even greater challenges in these areas than non-disabled people – are key to highlighting these important areas, so that resources and programming can be directed towards addressing them more effectively.

The baseline data as it exists now could and should be improved – but reducing the frequency of its publication (currently, annual for 'disability and housing', 'disability and employment', 'disability and well-being' and 'disability and loneliness', proposed to change to 'biennial', or every two years) would clearly be counterproductive.

Mortality

Our work on homelessness and acute housing need <u>includes</u> attention to the topic of homeless deaths here, and the factors contributing to them. We have written to numerous authorities (the Northern Ireland Housing Executive, the Police Service of Northern Ireland, the Department for Communities, the office of the Coroner) for information, but have found barriers to establishing the number of such deaths here as – unlike in England and Wales – the data was not collected and published. Again, ONS efforts in this regard served as an important benchmark to us.

The government's proposal for the ONS to cease collecting and publishing this data is, in this context, a real setback. Northern Ireland, like the Republic of Ireland and much of the rest of the UK, is facing a crisis in housing affordability. Increasing numbers of households are being declared officially homeless, and for the first time, significant numbers of them are being

placed in hotels due to the lack of hostel beds or single let temporary accommodation. As homelessness and housing need visibly rise, it is difficult to understand how a government genuinely seeking to combat these issues that cripple people's lives could suggest terminating, rather than improving and expanding, a project to collect and systematise data on their impact.