Improving Survey Accessibility by Raising Interviewers' Awareness of Dementia and Autism

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**Abstract**

ONS aims to ensure that everyone can take part in its surveys, regardless of any impairments they may have. Since 2009, guidance has been provided to interviewers on making surveys accessible to people with visual or hearing impairments, physical disabilities and learning disabilities; the guidance on some other conditions was less well-developed. Although there are many conditions which may affect someone’s experience of taking part in a survey, dementia and autism are each estimated to affect about 1% of the population and present particular communication challenges.

ONS has occasionally been criticised – in complaints from respondents or their carers – for distressing vulnerable respondents by asking them to take part in surveys. In responding to these complaints we point out that, where possible, we want to ensure that people with dementia or autism have the opportunity to have their voices heard and their circumstances taken into account in our surveys because they are affected as much as anyone else by the decisions made on the basis of our survey results. Our aim was both to improve the experience of taking part – or being asked to take part – for people with dementia and autism and to reassure their families and carers.

At the start of 2015, we launched an initiative to increase interviewers’ awareness of dementia. We had the support of the Alzheimer’s Society both in this initiative and in our attempts to try to include people with dementia in our surveys. An article about our work was included in one of the 2015 editions of their members’ newsletter. During 2015, two thirds of all ONS interviewers became "Dementia Friends" at sessions delivered by volunteers at local meetings. Each participant was given a forget-me-not lapel badge to show that they had completed the session. Alzheimer’s Society provided us with written tips on how best to communicate with someone who may have dementia.

We are now working with autism charities to develop awareness sessions for interviewers on autism spectrum conditions. It is estimated that autism affects 1 in a 100 people and that only 15% of people with autism are in full-time work. Since statistics about employment are among ONS's key outputs, there is significant potential to bias our results if we are unable to interview people with autism.
Many of the principles of communicating with people with dementia and autism are also applicable to other respondents who do not cope well with taking part in a survey, so will be of wider benefit.