

Sandwell Metropolitan Borough Council

Insight Research – Social Isolation in Carers



Background and Objectives

Social isolation is defined as a complete or near-complete lack of contact with people and society. Owing to its **profound negative impact** on health and wellbeing, **reducing social isolation** is a key priority for many local authorities.

In the 2011 census, **6.5 million** UK citizens reported being a **carer**. The number of citizens providing full-time care in the UK is increasing rapidly, and is likely to increase further still as our population ages (estimated at over 10 million in 2016).

83% of carers report that they have felt **lonely** or **socially isolated** as a result of their caring responsibilities. However, social isolation in carers is poorly understood. The focus of HCPs and services is typically placed on the needs of the cared-for individual. Carers **save** statutory services a **substantial sum of money** each year – therefore it is essential that they are supported to enable them to continue in their caring role.

ICE was commissioned by **Sandwell Metropolitan Borough Council** - which has a sizeable carer population - to **explore** the experiences of carers in the borough with the following objectives: to understand the **causes of social isolation** for carers, to identify what carers need to **prevent** or **manage** social isolation and to explore the wider impacts of caring responsibilities.

Methods

As part of a wide reaching insight project, ICE conducted a structured literature review, insight groups, individual depth interviews and a 7 day ethnographic diary exercise.

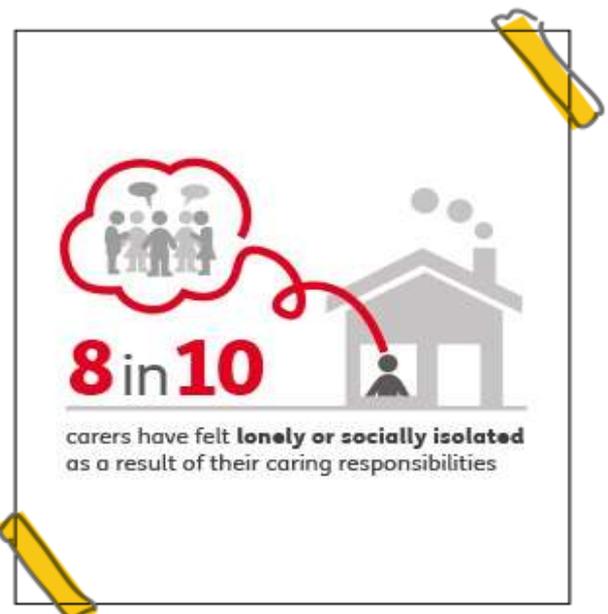
The innovative research techniques ICE employ don't just seek to explore **what** citizens do and **how** they do it. They are designed to continually explore the **WHY?** ICE used clean language, laddering (means-end chain), projective exercises and constructed scenarios to understand the carers' emotions, attitudes, values and beliefs that drive their behaviours and decision making.

The range of carers in this study included those caring 50+ hours per week, elderly carers, carers caring for individuals with slow progressing (e.g. dementia) and sudden onset (stroke) conditions, parent carers and carers who were recently bereaved.

Key Findings

Being a carer is like what?

Carers' lives revolve around their caring responsibilities. They describe their role as "living someone else's life", with their responsibilities "**taking over**", "being **24/7**" and being a "**life change**". Caring was also described as being "**hard work**" and a "**millstone**". The carers discussed caring as being **tiring, frustrating** and **getting no rest**, further suggesting it takes over their lives.



Carers are pushed to their physical and mental breaking point by their responsibilities.

How do carers become socially isolated in Sandwell?

The following were identified as key causes of social isolation for carers:

Life revolves around caring – unable to leave the home, unable to leave cared for individual alone; perceive no time for social activities and unable to make spontaneous social plans.

Carers have to stop working – as they no longer attend a workplace, they lose contact with colleagues and have fewer opportunities to be invited to or arrange social activities.

Carers lose contact with friends/family – friends/family stop visiting, the cared for individual doesn't want guests and friends/family stop inviting carers as they often have to drop out of plans.

Carers lack the confidence to ask for help – they have less contact with others so less opportunity to ask for help. They perceive that others don't understand their experience, and negative experiences of services reduce confidence further.

What do carers need to improve social isolation outcomes?

The carers involved in this study were **socially isolated** and reaching **physical** and **emotional** breaking points. They need more breaks from their caring responsibilities and increased support and understanding from friends/family and their communities.

The onus is currently on carers to ask for help, but given they lack the confidence to ask for help, they require better signposting to help and more offers of help/support.

Many of the services available in Sandwell, such as **respite**, are designed to give carers a break. However, awareness of the availability of such services was low, as is carers' confidence to access them, and there were no defined pathways or signposting at the point of need. This results in many services being accessed **reactively**, if at all, and means they do not currently help **prevent** social isolation.

What's next?

This insight research project resulted in the development of a carers' journey. ICE mapped the causes of social isolation against key events/time points in the carers' journey and then plotted them against carers' identified needs. Six evidence-based recommendations that will inform future commissioning were developed based around this journey. These recommendations included a service provision review, pathway redesign (joining up carers' journeys with that of the cared for individual) and a public awareness campaign (designed to increase awareness of available services and support, promote understanding and champion the benefits of carers).

For more information please contact:

Dr Adam Moore
adam.moore@icecreates.com
0151 647 4700

ice **make
better
happen**