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Briefing: Young adult carers and the 'don't know' option

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SUMMARY

The proposal to offer a 'don't know' option to young people being asked if they are a carer, was developed by young adult carers, with the support of the ESRC Centre for Care, addresses a persistent problem in identifying carers. People that provide unpaid care for family members may be asked whether they are a carer. This could be accompanied by explanations and examples to encourage them to relate to this label. Many people who provide unpaid care experience doubts about whether the term 'carer' applies to them. A 'don't know' option, alongside 'yes' and 'no' would be a small change with a big impact.

THE PROBLEM OF NOT KNOWING IF YOU ARE A CARER

Thousands of children and young people are identified as carers and some go on to benefit from support. Many, however, are never identified and are missing out on specialist services for themselves and their families. The Children's Commissioner for England estimated that four out of five young carers were not receiving support from their local authority. Carer services rely on a process of identification to target their support and this can be difficult to action for several reasons. Children, young people and their families might be unfamiliar with the term 'carer' and not come across explanations that help them connect it with their circumstances. When young adult carers think about themselves as, for example, a daughter, son, sibling or grandchild, they might think that their care role is already described by those terms and the carer label must mean something else. For others, they fear that a process of carer identification could trigger intrusion, judgments, assessments or families being split apart. The association of carer services with the charitable sector can trouble some people, who might infer that only the most in need should get that help and feel there are others that need it more than them. This multitude of cultural, linguistic and social barriers may not be spoken out-loud but it affects many children and young people by pushing them away from the services that want to support them.

The identification process might cause them to recall negative experiences that prevent them from engaging with the process. In some cases a young adult carer might have tried to share that information in the past and experienced little benefit as a result or they might have faced misjudged or punitive responses. When another opportunity comes around, they may then avoid declaring their carer status to avoid more of the same negative experiences.

In the face of that complexity, a verbal question or a self-completion form with a question asking whether someone is a carer and a 'yes' or 'no' option might drive people towards opting out. This is made worse by the frequent lack of information about what happens if you do identify yourself as a carer. Yes/no thinking about carer identification jars with the complexities of carer identities. The lack of information about what happens when someone is identified also misses an opportunity for people to identify themselves with more confidence and to be informed of support available.

THE PROJECT

A young adult carer participatory action research project in Solihull, West Midlands, was started to explore young adult carers' experience of identifying with support services. This was run by the ESRC Centre for Care, as part of work on care in the life course and at points of transition within people's lives. Recognising the importance of young adult carers voices within research on identification and support services, the project began by involving young adult carers as co-researchers who could direct the project, carry out research and generate ideas for change. With the support of Carers Trust Solihull, four young adult carer co-researchers analysed the ups and downs for young people accessing carer support services. The group built up an understanding of the state of not knowing whether you are or aren't a young adult carer. They shared the impact this has, especially when young people are confronted with yes/no options. 'No' often seems safest and this repeatedly cuts off young adult carers from services that could be of help. Whether the promised funding was sufficient, given what the Government hoped to achieve, was immediately questioned by care providers, campaign groups, research organisations, and trade unions (Disability Rights, 2021; Carers Trust, 2021; Carers UK, 2021; UNISON, 2021; Kings Fund, 2021).

OUR IDEA FOR A SMALL CHANGE WITH BIG IMPACTS

This group explored an option for an alternative way of approaching the identification process. When asked if someone is a carer, beyond 'yes' and 'no', we suggest that there could be a 'don't know' option. These three potential answers would be accompanied by a statement explaining the process that would follow for anyone identified as a carer. This would have the potential to reassure people that a supportive process would follow. There should also be transparency about the risks and negatives that might follow identifying as a carer, clarifying that it is people's choice whether they disclose this information. This new approach to identification would clarify the benefits and risks of identifying yourself as a carer. It would also engage with the complexity and ambiguity of being a carer, which makes it hard to know what box to tick.

Being a young adult carer frequently brings phases of being in a 'state of don't know' about whether you are a carer or not. The 'state of don't know' is recurring, varied and cuts across administrative processes and policy areas. The 'don't know' option could be a thoughtful and practical response to this and be relevant to schools, colleges, universities, GPs, hospitals, social services and housing services. The engagement of a range of services in improving the process of identifying young adult carers would have a positive impact, as, due to their age and the transitions of young adulthood, young adult carers are connected to a changing set of organisations.

WHY THIS WOULD MAKE A DIFFERENCE

From our research we are interested in the potential for a 'don't know' option to increase the number of young adult carer identified, increased the number of young adult carers getting support, increase the number of families considered for social care support for someone with care needs, make identification available to people earlier and reducing the period that someone might be undertaking care without support. For the 'don't know' option to make the most difference, someone ticking a 'don't know' box should be offered an informal and supportive conversation to help them understand their options about sharing information about their caring status. It should also be accompanied by information about what organisations offer to support people that are carers, so that people are proceeding to identify themselves with the confidence that they will benefit from the process.

NEXT STEPS

We would welcome discussion with policy-makers, organisations and young adult carers that are interested in initiatives to improve the identification and support process for young adult carers.

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Please get in touch if you would like to know more, or to work with us on related issues, by contacting our support team:

Website: centreforcure.ac.uk



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