

New assessment form likely to underestimate disability

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Changes to the disability living allowance (DLA) form which distributes over £13 billion annually in benefits, may lead to reduced financial support for claimants, new research suggests.

Under the existing DLA assessment people with long-term health conditions or disabilities can claim between £21.55 and £134.40 per week to help support their everyday needs. The form itself involves a 55-page self-report questionnaire which is completed either by the claimant, or if necessary with the assistance of a caregiver. However research which has examined how claimants and their informal carers arrive at answers for the DLA questions has revealed high levels of disagreement. Specifically people with disabilities are more likely to downplay the severity of their disability and resist the way the form portrays them as 'dependent'.

In a study conducted by Dr Alex Gillespie, from the London School of Economics, and Dr Helen Moore, from the University of Birmingham, people with acquired brain injury were filmed completing the DLA form with their informal carer (in most cases their spouse). 26% of questions led to disagreements between caregiver and care-receiver, and of these 88% involved participants with brain injury arguing for a lower level of disability.

"Contrary to what people might expect with a claim for financial support," Dr Alex Gillespie says, "people with brain injury appeared to downplay the extent of their disability. This is because the participants with brain injury resisted the way the DLA form was negatively positioning their identity as dependent"



Positioning is a term which refers to the way in which people are located, described and implied within communication and plays an integral role in how identities are constructed. Simply put, people with brain injury often resist having to list all the ways in which they are dependent upon others, and, instead, they want to emphasise their abilities and independence.

While claimants are often likely to downplay the extent of their disability, in contrast caregivers would often argue in the opposite direction for a more dependent view of the claimant. Such divergent views may be the result of caregiver and care-receiver having access to different streams of information.

"We have seen that in other care-settings informal carers often conceal the burden of care to protect the positive identity of the care-receiver. People with brain injury are not always aware of the "back-stage" support that a caregiver may quietly perform. This can lead people with brain injury to overestimate their independence. . It is also true that caregivers are an important stakeholder in the DLA form because success in a claim increases formal support thereby lessening their own burden of care. Thus, a tension can exist between the claimants who argue down care needs to protect their identity, and caregivers who argue up to protect the claimant from misrepresenting themselves and losing access to further support."

Implications for the new disability assessment

Currently the DLA form is in a process of being replaced by the Personal Independent Payment form (PIP) which seeks to provide a more "objective" measure of how long-term health conditions and disabilities affect people's everyday life. In the new scheme claimants will still complete a self-report questionnaire but there will be greater use of face-to-face interviews. These interviews will focus on the person with the disability, and the perspective of the care-giver will have less influence. Moreover, the presence of an interviewer could produce distorting self-

presentation dynamics. For example, it could lead care-receivers to further resist being positioned as dependent, and, it could inhibit care-givers attempts to argue up the care needs out of concern for appearing domineering to the interviewer.

Dr Gillespie therefore has concerns about the new format. "It's not clear in what way the new measure will be more objective" he suggests. "By having a procedure which privileges the care-receiver's account, a much more optimistic assessment of care needs is likely to be produced, and one which will undermine the voice of the people who are actually providing informal care. Arguably if care-receivers are to obtain the benefits to which they are entitled through the new PIP, they will need to fully subordinate their identity to their disability."

NOTES

1. Based on the findings from a research project on 'Translating and Transforming Care: People with Brain Injury and Caregivers Filling in a Disability Form', funded by the University of Stirling and led by Dr Alex Gillespie, the London School of Economics, and Dr Helen Moore, The University of Birmingham.
 2. The research used the UK Department of Work and Pensions DLA claim form (version DLA1AAdult November 2009).
 3. The study recruited twenty-two dyads (n=44) through the Brain Injury Rehabilitation Services within the NHS and Headway, a charity that supports people with brain injury. All participants were over two years post brain injury acquisition, with no history of co-morbidity or alcohol/substance abuse.
 4. The study was conducted during a series of home visits by Dr Helen Moore.
 5. The data collection involved video recording of 22 participants with acquired brain injury completing a section of the DLA form with their spouse entitled "help with your care needs during the day". These included questions 35-48 of the form. For ethical purposes four questions were removed due to their sensitive nature including toileting (Q36) showering (Q37) dressing (Q38) and eating (Q39).
 6. The reference for this research is: Gillespie, A., & Moore, H. (2015). Translating and transforming care: People with brain injury and caregivers filling in a disability claim form. *Qualitative health research*, available online open access at <http://qhr.sagepub.com/content/early/2015/03/19/1049732315575316.full>
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