

Personal assistance relationships are complex and need support, study finds

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Personal assistance relationships are usually empowering and flexible for both employer and workers, but can become emotionally fraught and even wounded, according to a report launched today.

Findings of the study into the diversity and complexity of relationships between disabled people and personal assistants will be presented in London today, with recommendations for how to make these relationships work better.

Personal assistance (PA) is a model of support where disabled people take control of recruiting, training and managing the people that help them. Personal assistance differs from other forms of social care, such as domiciliary care, because the disabled person is in control of how they are supported. In England, an estimated 65,000 disabled people are employing 145,000 personal assistants (Skills for Care 2016).

The disability rights movement pioneered the model of personal assistance, seeking to distinguish between tasks and emotions. This new study shows that emotions are still at the heart of personal assistance relationships. The flexibility of the relationship is positive, but the lack of agreed meanings and rules can cause uncertainty around boundaries.

Prof Tom Shakespeare, from the University of East Anglia, said: "In the UK, disabled people are free to employ whomsoever they wish and organise support without oversight from third sector agencies. This freedom offers great rewards—when disabled people have control over their support arrangements it leads to better outcomes.

"But there are also risks, PA relationships frequently involve conflict, and without support managing PA relationships can be demanding and emotionally fraught. We investigated the nature of the role of [personal assistant](#) and how it is

experienced, the power dynamics and how conflict or other difficulties are negotiated or avoided so that we can make recommendations to improve the success of these working relationships.

The project was funded by the Economic and Social Research Council. Qualitative interviews were conducted with 30 disabled people and 30 personal assistants, together with observations of the support relationship in action.

Prof Shakespeare said: "The concept of emotional labour is well known from the care literature. But we found that emotional work was required from both the [disabled person](#) and the personal assistant, in order for the [relationship](#) to go well.

While most of the time, personal assistance relationships are flexible and empowering, every single one of our respondents had experienced conflict at some point. At the extremes, we found [disabled people](#) falling in love with their assistant and experiencing heartbreak. We also found personal assistants taking advantage of their employers, and even stealing from them."

A number of recommendations will be presented at the launch event, from seeking a good match between employer and worker and vetting applicants to clear dialogue and third party resolution.

The report launch event will comprise a presentation of the findings by members of the research team, together with a panel discussion of their implications with Tracey Jannaway (Independent Living Alternatives), Jane Campbell (Baroness Campbell of Surbiton), and Mark Harrison (Equal Lives).

A preview of a new online training package produced for PA employers and workers to help these relationships go better, illustrated by cartoonist David Shenton, will also be shared.

Provided by University of East Anglia

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