Dear MP,

I am writing to you as a service user/ family member of a service user/ friend of a person with spinal muscular atrophy (SMA) (delete as appropriate) to express my concern about the staffing crisis for personal assistants (PAs) which is making it more difficult for me to go about my day-to-day activities.

The role of a Personal Assistant (PAs) is a lot broader than that of a ‘carer’ in the traditional sense, and as such their value is often misunderstood. Similar to a carer, many people with SMA who employ PAs are fully reliant on them to get up, get dressed, to wash and use the toilet, to eat, drink and so-on. However, on top of that, my PA helps me (add social activity such as to get to work, run my own business, attend hobbies) which makes me feel like a contributing member to society. Because the role and value of PAs is often misunderstood, they have been overlooked in Government policy and social care initiatives which has led to a serious recruitment crisis.

People with SMA, who are eligible, are provided with their own care package to use at their own discretion through the ‘Direct Payments’ scheme . This includes employing our own PAs who cover a broader remit of support so that we can live as independently as possible, without relying heavily on our family or care agencies. Because a PA is with us full-time, PAs are more aware of our individual needs and better able to support us, compared to a carer who only may undertake certain tasks and only comes into the home for a few hours here and there.

However, even with the direct payments scheme, the budget allocated to a ‘care package’ funding is only enough to offer a low hourly rate which is insufficient to attract potential PAs. As such, prospective PAs will earn much more through other similar roles such as house cleaning or dog walking, for example. Prior to Brexit, many in the disabled community therefore recruited European PAs who were willing to accept a lower wage. Now the potential pool of employees has been further reduced by COVID-19 in terms of availability of those who are vaccinated – which is a must for many of us whose health condition makes them vulnerable.

**As my local MP, I am asking you to take forward the following asks to address the PA recruitment and retention challenges facing the disabled community:**

1. **To push for individual disabled employers to be added to the expanded the Health and Care Visa Scheme**

The Government has expanded the Health and Care Visa to include care workers and home carers to the Shortage Occupation List. However, individual disabled employers are unable to apply for a sponsorship license unless they are not recognised as part of the list of eligible employers.

1. **Allocate additional funding to improve care package provision to improve recruitment of PAs**

In December 2021, an additional £300 million was announced to support local authorities, working with care providers, to recruit and retain care staff. This is in addition to the £162.5 million Workforce Recruitment and Retention Fund that was announced in October 2021. It is great to see such investment going into social care, however some of this funding needs to be added into the care packages budget allocation to attract more staff.

1. **Review progress made by local authorities to develop and deliver plans that will support individual disabled employers to recruit and retain their own staff.**

It was also announced in December 2021 that local authorities will have a key role in supporting local providers to recruit and retain social care staff. However, it would be reassuring to hear how local authorities will remain accountable to tackling this crisis, and within that, have a target to include improving personal assistant recruitment for disabled people.

I appreciate you taking the time to read my concerns and hope you will take these asks forward. If you have any further questions or require further information about these issues, please email: office@smauk.org.uk to discuss how you can help.

Yours sincerely,

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