

National Care Service – consultation response from Spinal Injuries Association

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Introduction and Background

There are currently more than 50,000 people in the UK with a spinal cord injury (SCI), and on average a further 6 people per day (approximately 2,500 per year) are diagnosed with a SCI and must come to terms with the devastating, life-changing and life-long impact of their injury.

Symptoms of a SCI depend on the severity of the injury, and its location on the spinal cord, but may include partial or complete loss of sensory function or motor control of arms, legs and/or body (paraplegia or tetraplegia). A spinal cord injury also affects the systems that regulate bowel or bladder control (resulting in incontinence), breathing, heart rate and blood pressure. Most people with a SCI experience chronic neuropathic pain.

Spinal Injuries Association (SIA) believes that every SCI person must get the specialist care and support they need to lead a fulfilled, happy and productive life. Failure to do so runs the risk of SCI people not being able to effectively manage both the physical and mental aspects of their condition, which will inevitably lead to medical issues that will require time-consuming and expensive treatment and consequently put even greater pressure on the NHS.

For over 47 years, SIA has built a vision of a fulfilled life for everyone affected by SCI. We are a user-led organisation guided by 13,000+ members, spinal cord injured staff, volunteers, and trustees whose needs and interests inform and underpin our strategic direction.

SIA's founder and president is Baroness Masham of Ilton, who became spinal cord injured at level T5 following a riding accident in 1958. The Baroness is an active member of the House of Lords and is especially vocal on health and disability issues, particularly spinal cord injury. When Baroness Masham founded SIA in 1974, her main concerns were the lack of specialist medical care available to all newly injured people, and the lack of information and advice available to SCI people on leaving hospital. Out of these twin concerns, the Spinal Injuries Association was born.

Everything SIA does aims to support, guide, and empower SCI people on their unique journey post-injury, so that they can survive, cope, adapt and ultimately thrive as positive, contributing members of society.

SIA recognise that to achieve a fulfilled life for all injured people and their families, in their wide diversity, a more coordinated, accessible, expert, and vociferous community is needed. To achieve this, we are building an association for all – one that can support our sector to be greater than the sum of its parts – growing capacity and expertise, raising voice and influence, and coordinating increasingly accessible support and services to all who need it.

All the 50,000+ people living with a SCI in the UK face a long-term situation of ever decreasing support services, at best meeting medical and basic-care needs. Swift and timely specialist rehabilitation is essential for newly injured SCI people to prevent further medical and psychological complications later in life.

Ongoing rehabilitation, mental health support and even basic healthcare and social care needs for SCI people and their families are locally and nationally under-resourced, making the chances of a fulfilled life even harder to achieve. SIA's members who employ health and social care workers directly are some of the most seriously disabled people in society, amongst the most vulnerable, and with the most complex needs. The crisis in the adult social care sector, and the constant fear of being left without life-sustaining care, has left many SCI people desperate and fearful.

SIA's Support Line has been inundated with telephone calls and emails from the increasing number of SCI people who are struggling to access the skilled and well-trained carers they need to help them lead a fulfilled life. This has particularly been the case with live-in carers, a role that the government incorrectly believes can easily be done by young British people.

Much has been written about the social care crisis, but SCI people know better than anyone the urgency of the situation. The reality is that it's not a case of relying on carers to help the individual flourish, it's a case of relying on carers to make sure SCI people stay out of over-stretched NHS hospitals who are generally unable to cope with the complexity of caring for someone with multiple and complex needs such as a spinal cord injury.

The stark reality is that SCI people who use carers completely depend on them to stay alive.

National Care Service

Social care has been repeatedly deprioritised and defunded by successive governments. This displays a lack of care for disabled and elderly people who may require care.

The current national debate around the future of social care is also plagued by a misconception that social care is only for elderly people, and is focussed on those residing in care homes. In reality, one third of those who receive care are adults of working age. We need a system that addresses their needs, and their right to a fulfilled life.

SIA believes that a National Care Service is needed to provide care that is free at the point of use. It should be focussed on the right to independent living. This does not mean the right to live by oneself (indeed, in some cases fulfilling the right to independent living may require a live-in care worker) but the right to live with the same opportunities, choices and control as everybody else in our society.

SIA believes that this right to independent living, as is set out in the UN Convention on the Rights of Persons with Disabilities should be brought into UK statute. From there, a National Care Service would have a clear aim for what it must achieve for those who require care.

The Core Principles of a National Care Service:

SIA would like to see the creation of a National Care Service that provides personal care to those who need it regardless of their circumstances or income. It should be a truly national service that is free at the point of use, just as the National Health Service is.

Importantly, it must also be a universal service, that meets the needs of all who require care, regardless of age or living arrangements.

A National Care Service must be genuinely co-produced and co-managed to allow service users or future service users in its pre-launch phase) maximal input to ensure that it is designed to work for those who receive care. This means that service users will not just merely be consulted but will be well represented throughout the governance structures of the service.

As has been well documented, the current care system suffers due to the poor conditions and poor pay of its workforce. This results in consistent shortages of care workers, a problem which has only intensified since Brexit due to the large numbers of care workers from EU countries which the UK has historically relied upon. This is accompanied by poor morale and motivation for existing care workers which also results in a poor standard of care.

It is therefore essential that care workers must be well paid for the important work they do as part of a National Care Service, regardless of whether they are employed by the public or private sectors. Acceptable standards of minimum pay must be enforced across the sector to ensure that the undervaluing of the sector does not continue.

This minimum pay floor should be above the National Minimum Wage that is legislated for across the entire UK economy. Providing intimate personal care requires a substantial level of trust and is of utmost importance to service users who absolutely rely on care workers to enable them to live their lives. It should therefore be a career which actively fosters reliability and commitment.

It should also be a career which entails training and educational opportunities to its workforce as well as career progression. This will not only help to raise the profession in the eyes of the general public, but it will also help the poor retention rates in the profession. Ultimately, this will lead to a better standard of care across the board.

A National Care Service must also work hand in glove with the National Health Service as well as other vital public services which disabled people rely on, as well as the Department for Work and Pensions. A major problem for our members is repeatedly being assessed and re-assessed by various public agencies who do not share information, and all often require proof that unchanging needs have not evolved to require less care.

It is also worth highlighting that without well-funded and well-functioning universal public services, the right to independent living cannot be fulfilled. We must also address the dearth of accessible transport, accessible leisure facilities, accessible employment opportunities and accessible housing if this is to be achieved.

As the National Care Service is a universal service, we believe it must be paid for via general taxation. We are cautious of any moves to fund the service through a wealth tax. This is partly because this is what has frequently been suggested by previous governments and it has come to nothing, but partly because it largely rests on the idea that the service will be used by elderly people who are likely to have taxable assets and generational wealth (as per the thinking of the Department of Health up until the 2010 General Election). A National Care Service must be truly universal however, and cater for the needs of everybody who requires care, not just elderly people. Any funding system that is premised on only or primarily older people using the service would be too vulnerable to future governments limiting access to the service for those who are of working age and require care.

Additionally, it should not be funded through any form of local taxation, due to there being fewer wealthy areas of the country where a substantial tax based to fund the service may not exist. We must aim to move away from the postcode lottery where levels of service vary wildly across the country, and move towards a universal system that provides the appropriate level of care for everybody.

Emphasising that it is a universal service funded through general taxation, available to anybody who requires care, would demonstrate that every single person in our society may need care at some point in their lives due to age, illness or physical trauma.

Although the service must be free at the point of use, many of SIA's members benefit from the flexibility and agency that is afforded to them through Personal Budgets or Direct Payments that allow the service user to become the direct employer of those who provide their care. The introduction of this system was a major win for the disability rights movement over the last 30 years, and it is of utmost importance that a National Care Service does not threaten the opportunities for independent living that Personal Budgets or Direct Payments afford.

It is notable that the Scottish government did not fully lay out their position of Personal Budgets or Direct Payments with the current introduction of their National Care Service.

That same cannot be repeated for the introduction of such a system elsewhere in the UK. Personal Budgets or Direct Payments, or an alternative system that enables service users to be in full control of their care, must remain for those who request it after the creation of a National Care Service.

Although we believe care itself should be free at the point of use, if hotel costs are to remain in place for residential care (the costs of the actual accommodation, minus the care costs), we believe they must be capped over the period of a lifetime, as per the Dilnot Commission Report. Due to serious shortage of accessible housing in this country, it is not uncommon for our members to be housed either temporarily or permanently in residential care settings, despite being significantly younger than most of the other residents. This normally comes at huge cost to their mental health and recovery.

Conclusion

With political will, we believe the development of a National Care Service is eminently achievable within the course of a single parliament.

However, the most immediate action that any government should take to help address the care crisis is to provide local authorities with the funds they need to meet current demand, at a rate which allows them to pay care workers an attractive salary. Failure to do so will simply exacerbate the current crisis in the care sector, and lead to more spinal cord injured people being unable to lead the fulfilled and productive life they are more than capable of achieving with the right level of support.

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