

3 September 2020

Janet Finch-Saunders. AS/MS Cadeirydd/Chair  
Y Pwyllgor Deisebau / Petitions Committee  
Senedd Cymru / Welsh Parliament

Dear Janet Finch-Saunders

**Re: Petition P-05-914 Equal Access to Health Care for the Disabled**

Thank you for the opportunity to respond to the request from the Petitions Committee at the Welsh Parliament to *ensure 'it is a legal requirement for all GP surgeries to have wide, adjustable treatment beds and hoists available for the use of disabled patients, so that they can be examined whenever there is need'*.

Shine supports 12,000 individuals living with spina bifida and/or hydrocephalus (SBH) and their families across England, Wales and Northern Ireland. Our charity has over 50 years of experience and insight into the challenges faced by people whose lives have been affected by spina bifida and/or hydrocephalus.

In Wales, Shine Cymru represents a community of over 800 individuals (babies, children, and adults) living with spina bifida and / or hydrocephalus. Our team of four Support and Development Workers provide advice, information and direct support to those individuals and their families on a wide range of issues directly related to the conditions.

Spina bifida is a little-understood and complex condition, affecting a person's physical, mental and learning development. It is congenital, and many people will have double-incontinence and be prone to risks such as kidney infection and kidney failure. People with spina bifida may have a higher chance than people without spina bifida, of developing bladder cancer, and of developing it at a younger age<sup>1</sup>.

Mobility is always severely impacted from birth, and the majority of children growing up with the condition become wheelchair-users. Most will develop hydrocephalus (water on the brain), although hydrocephalus can occur at any time during a person's life. Both conditions can have a huge impact on a person's ability to perform daily tasks, live independently, socialise and sustain employment. They also have an impact on a person's cognitive function, learning ability and mental well-being.

Advances in medical technology and treatments, greater understanding of the conditions, more positive attitudes in society and new ways of communication have brought change for people with SBH. Individuals with the conditions are living into old age, and many are enabled to do things that only a few decades ago

would have been impossible. Yet challenges and barriers faced by our members from birth and throughout their lives of accessing the right health care and treatment at the right time remain.

Shine's 1000 Voices survey 2020 indicates that 40% of our adult members believe that their GPs 'poorly understand' spina bifida and its complexities, and it is this lack of understanding that leads to a delay in referrals to specialists for early diagnosis and treatment. See Shine's information for general practitioners<sup>ii</sup>

The survey also reveals that only 20% of adult members over 25 years of age, living with spina bifida, have regular check-ups with their GPs, with a huge 73% only ever presenting to a GP when they are ill and needing treatment, as opposed to preventative health advice and interventions. Yet our members report that they feel they are not being properly examined when they feel unwell and/or present with symptoms at an early stage due to the lack of facilities at GP surgeries.

Our members tell us that they often present multiple times to a GP with a suspected urinary tract infection, a common issue for people with spina bifida, yet rarely are they referred to a specialist for investigations into the cause, and subsequent appropriate treatment. They report that they are much more likely to be prescribed course after course of antibiotics for a recurring health issue that can eventually lead to much more serious complications.

We understand this to be the case with Shine Cymru member, Tracy Locke, who has called on the Welsh Parliament to review access to examinations and treatment. Had Tracy had the access to the appropriate equipment to enable the examinations she needed but also to health professionals who better understood her condition, Shine Cymru firmly believes that her bladder cancer would have been detected at a much earlier stage.

Barriers to accessing the right equipment and appropriate and thorough examinations reported by our members with spina bifida and staff in Wales include:

- Transferring onto an examination table with mobility issues, whether the individual is a wheelchair user or not, is a challenge because examination tables are not wide enough and / or the height of some tables is not adjustable.
- Not all surgeries have hoists / slings to aid transferring.
- Use of equipment sometimes needs to be pre-booked but often this does not happen, and appointments have to be re-arranged.
- Two members of staff are often needed to operate a hoist, and this is not always possible, and appointments again have to be re-arranged.
- Hoists/slings are not routinely serviced and therefore may be lying unused, creating an additional barrier to accessibility for important examinations for some.

Members report that this lack of access to appropriate equipment and examinations exists in both the smaller, more traditional settings and also in the more modern, better resourced and exemplar primary care centres. Equipment is simply not available, leading to referrals and long waiting lists for other clinics or services.

Access to the Welsh Screening for Life programme in Wales is also difficult for people with spina bifida. Whilst there are numerous references and resources on the Screening for Life website in relation to supporting people with learning difficulties to access the screening services, we cannot find any reference to accessible provision for people with physical disabilities (e.g. women with spina bifida and mobility issues, but who are not wheelchair users, find breast test screenings very challenging as they have difficulty standing and balancing for long periods of time). Informal discussions with Screening for Life staff by our staff have not provided any further clarity.

Many members have to travel out of county to access the Screening for Life services.

Our members also report this lack of access is compounded for wheelchair users, either due to practical access arrangements not being in place, and/or lack of staff knowledge to manage the screening tests / examinations for a wheelchair user.

Shine Cymru has long campaigned for improved access to paediatric and adult continence management services across Wales. Whilst statutory frameworks and toolkits have been developed and a variety of reports published, in reality little has changed since Shine Cymru's 2014 report into continence services<sup>iii</sup>. Services remain disjointed across Wales and do not meet the demands of continence issues of people with spina bifida of all ages.

Our adult members and parents of children with spina bifida tell us that access to continence services and regular, routine check-ups are limited and more often than not, our members are only seen when they present with an issue, yet we know that early intervention with continence management can avoid serious complications, improving health and well-being outcomes during childhood and adulthood.

Approximately 24% of our adult members over 25 years of age, living with spina bifida, have had unplanned, emergency admissions to hospital as conditions have worsened and treatment has been delayed. The overwhelming reasons for these emergency admissions are to treat urinary tract infections (UTIs), Urosepsis, skin/tissue breakdown and/or sepsis which develop as a direct result of lack of access to the appropriate services, examinations, diagnosis and preventative treatments.

These on-going issues severely impact the health and well-being, and futures, of children and adults living with spina bifida in Wales.

Shine remains hugely concerned by the fragmented nature of, and access to, health services, examinations and tests for children and adults with spina bifida in Wales. Our experiences and research suggest that the current model of care requires people to become ill in order to access the treatment they need, by which time it is too late for preventative health care, as has been the case with Tracy Locke.

Shine has long advocated for access to a regular, specialist multi-disciplinary clinic in Wales, and we would welcome the opportunity to further discuss the scope for developing this approach for improved health services and treatment for our members across Wales with the Department of Health and Social Services and Local Health Boards.

Thank you again for the opportunity to provide evidence to the Petitions Committee. Shine remains committed to offering you full co-operation and support on this issue so please do let me know if you require additional information to inform your decisions.

With best wishes,



**Kate Steele**  
**CEO & Directorate Lead for Wales, Shine**

**On behalf of Mark Noakes, Chairman, Shine**

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<sup>i</sup> Rove K, Husman D, Wilcox D, Vricella G, Higuchi T *Systematic review of bladder cancer outcomes in patients with spina bifida (2017)*, Journal of Paediatric Urology

<sup>ii</sup> <https://www.shinecharity.org.uk/spina-bifida/adults-with-spina-bifida-a-information-for-general-practitioners>

<sup>iii</sup> Improving continence services in Wales - A Call to Action to the Welsh Government. Shine Cymru 2014