



All Party Parliamentary Group on Spinal Cord Injury

Wednesday 8th November 2023 from 3.00-4.15pm

Present:

Chris Stephens MP

Apologies:

Bob Blackman MP
 Ben Everitt MP
 Helen Morgan MP
 Andy McDonald MP
 Mark Tami MP
 Margaret Greenwood MP

Secretariat:

Dharshana Sridhar, Spinal Injuries Association
 Glyn Hayes, Spinal Injuries Association

1	<p>Welcome and apologies for absence.</p> <p>Chris Stephens MP welcomed everyone to the APPG meeting.</p> <p>The apologies for absence were noted as above and Chris explained he would be chairing the meeting in the absence of Andy McDonald MP.</p>
2	<p>Presentation: by Karen Hood, Director of the Injured Players Foundation on ‘Supporting and Protecting the Rugby Family.’</p> <p>Karen thanked the chair and started her presentation, explaining that the RFU Injured Players Foundation is a tiny charity, operating nationally with only three frontline staff, the rest support roles or part time.</p> <p>They are working with around 150 long term beneficiaries or clients or injured players: people who have sustained a spinal cord or brain injury The split is around 90% spinal cord injury and 10% the rest. In addition, the charity also deals with around 400 other incidents a year which could be potentially serious; the injured person might need some short term reassurance or may become a long term beneficiary of the charity. Karen thanked the RFU and England rugby for all their support and help with fundraising.</p> <p>The board of trustees come from the medical world, the research environment, finance or the Rugby community; with a couple of long-term beneficiaries on their board and another on staff. They are well integrated into decision making and strategy planning and improvement.</p> <p>The first area the charity concentrates on is prevention. Backed up by data, the probability of a catastrophic injury is roughly equivalent to that in the UK workplace which the HSE deem as an acceptable level of risk. The charity is doing a lot of work alongside the injured jockey foundation and similar charities across the four nations to learn the actual causes of the injuries and, with the evidence, look to see where they can make the most difference. Working with clubs, referees, coaches and the RFU to minimise the injury risk on pitch.</p> <p>After this comes the treatment and restoration of function. Working alongside spinal research and others to support them in areas such as neuromodulation and other emerging techniques. The charity recognises ongoing issues with pressure sores, obesity and isolation to name a few and signposts to other relevant organisations with the appropriate expertise.</p>

Next they look at Immediate support which is usually the period of initial rehabilitation. This is usually in a spinal injury unit where there is a massive benefit of working alongside the healthcare practitioners in their expert fields. Often the support of their team mates is what they need the most and this is where the IPF can facilitate this, with a visit rota so it's not all delivered on a Saturday afternoon.

The charity looks to remove the barriers to a quick discharge as the quicker someone can be discharged back into their community the better chance of a positive outcome and long term independence for the injured player. They help by buying or adapting property if required (before the disability facility grants come through) and they can shortcut the provision of wheelchairs

Community support or local team support is something they concentrate on as they recognise that they are dealing with rugby players and rugby fans first and that the spinal cord injury is secondary to that.

The charity takes a holistic approach to the beneficiary ensuring that they are brought back into the rugby family. On match days they are given the full hospitality package and can meet up with the players from their favourite teams. The IPF builds a lifelong relationship: regardless of what happens in the beneficiary's life in the, they are there for them.

The IPF works with a huge number of charities and organisations, universities and healthcare professionals so that they can get the right expertise for the beneficiary at the right time. They support the beneficiary throughout their life and encourage them to get involved with as many different activities as possible. They have had people winning archery competitions, people in wheelchairs sailing tall ships alongside able bodied people and have helped take groups skiing and travelling abroad. All these activities have a huge impact on the beneficiaries' lives, when they are contacted by the charity 6 months, a year or further down the line the message they get back is that they have the confidence to achieve anything now.

One of the charity's big successes was when they introduced the vocational rehabilitation programme. The current employment rate of 55% compares favourably with the national average for people with spinal cord injuries. They have also seen a large number staying in employment with others taking up voluntary roles or seeking education.

Another challenge for anyone injured with a spinal cord injury is getting to a rehabilitation unit on time. Waiting times are increasing across the board, for rehabilitation, assessments, equipment and funding for specialist equipment. The charity are taking on more and more applications.

The Spinal Injuries Association highlighted in their annual survey the social issues that people with disabilities face as well as aging which is a huge challenge. A lot of people rely on their parents or partners for care. As they age their provision is more at risk with those carers struggling to cope: this will then be a challenge for local authorities to try and meet the gap.

Direct financial support for beneficiaries was introduced for the first time last year; previously the charity predominantly funded activities. The cost of living crisis, with increased food and fuel costs meant that more immediate support was needed, and is likely to again this winter.

A video presentation was played about one of their beneficiaries named Tom. Karen explained that Tom was one of their success stories and that through their programme he has been able to finish University with first class honours, and since then managed to gain meaningful employment with two internal promotions.

The chair thanked Karen for her presentation and asked if the IPF provided social security advice for their members. Karen responded that they reach out to other charities for specialist advice. SIA for CHC and Aspire for benefit advice are two most used.

The chair asked if the charity are nationwide and Karen replied that though the RFU is the governing body within England, the charity work cross border with the other home nations and similar charities and bodies providing the services needed there.

The chair thanked Karen for her time and moved onto the next item.

3 **Cost of Living and Benefits Update presented by Aspire.**

The chair introduced Aspire: a charity who are involved in providing Housing Services, specialist housing information, adaptations, and finances for people with spinal cords injuries.

The representative from the charity was a welfare benefits advice manager who has been advising on benefits for over 25 years, starting with the DWP. They joined Aspire just over five years ago to work on their established specialist benefits advice service. The service was originally established to support clients with the transition from disability living allowance to Personal Independence Payment. Last year, Aspire supported nearly 400 clients with their benefits and have seen the demand grow every year. They support clients with any benefit related matter, whether it's general advice or benefits check form filling for personal Independence payment, allowance work capability assessments and we also see cases right through to appeal.

The social security system contains two types of benefits aimed at working age clients who are disabled or have health related conditions:

- Employment Support Allowance – a health element of Universal Credit
Entitlement to this payment is decided through a work capability assessment
- Personal Independence Payment
Intended to compensate individuals for the extra costs associated with disability

There are changes proposed to the work capability assessment which are likely to have a major impact on mutual clients.

The work capability assessment decides on how much an illness or disability limits capability to work and is actually worth £390 a month to anyone claiming it. It is decided on a points based system to see how well a claimant can actually carry out activities; taking into account their physical, mental, cognitive and intellectual functioning.

In September of this year the government announced a consultation on potential changes to the work capability assessment partly as a result of the disability white paper. Reasons given were the post pandemic opportunities afforded by hybrid or remote working: if a claimant doesn't have to travel or mix with other people then they will be able to manage their health conditions much better whilst at home and also earning a living. The concerning assumption seems to be that claimants with a spinal cord injury or any health condition or disability are all qualified and will have the skills and roles that could actually manage the jobs that could be done remotely.

In relation to the impact that some of these changes will have with someone that has a spinal cord injury for example loss of sensation, bowel and bladder impairment, issues with hand function in relation to grip and dexterity, mobility, pain, depression and anxiety.

The assessment is a points-based assessment, points are awarded based on the level of difficulty in relation to specified activities.

The activities that are going to be under review by the DWP are:

- Mobilised
It's proposed to remove this activity totally from the assessment or amend it and set the bar higher, only awarding points if somebody has difficulty mobilising up to 20 metres. Currently the bar is set at 50m. Any job will require workers to travel or to an office or another location. It could just be mobilising a few metres for example to a photocopier, getting to the toilet, or for a break getting a coffee. All of these things require some degree of mobilisation, so to remove this this activity is really concerning. The proposals don't take into account all these problems that our clients have.
- Bowel and bladder issues
These are very personal sensitive issues, often unpredictable. Routines can take a significant part of the morning or afternoon. The change that's proposed seems to imply that if a bowel or bladder accident in the workplace in front of a colleague, unless it's on

	<p>a daily basis actually would have no impact on the client. What's missing here is any reference in the proposals or consideration to the dignity or the anxiety and embarrassment that our clients would have as a result of a bowel or bladder accident, even if it was a one off incident you know you would experience all those things.</p> <ul style="list-style-type: none"> • Social engagement Early on in the injury many people suffer with anxiety and depression and other major issues with their mental health. Whilst remote working may help towards reducing these anxieties there's obviously some people that would still find things like video or telephone calls difficult as well as the additional demands and pressures that a job may entail. • Substantial risk Where a client is judged to be at substantial risk due to their mental or physical health, if they had to undergo work preparation and activities such as training or job search. Again many of Aspire's clients do not qualify solely under this route but it still has an impact on some of our clients as well as, wide reaching impacts mostly for those with mental health issues. <p>It is widely known that people living with a health condition or disability are far more likely to struggle financially due to the combination of low income and extra costs. Even before the cost of living crisis, the charity Scope estimated that disabled people typically experienced additional costs every month of £583 (additional need to use gas and electricity due to powering vital equipment such as electric wheelchairs, stairlifts, and hoists). The argument is additional cost of living payments have been made, however these do not compensate for the potential loss of the additional Health element which a lot of our clients potentially stand to lose by these proposed changes.</p> <p>The health element, although it's £390 pounds a month over the year, works out to be up to £4,680 so a huge, huge impact on many of our clients.</p> <p>Aspire very much supports those with a realistic prospect of employment and believe that people should have the opportunity and should take part in activities and embrace opportunities to make their lives better. However, there's no doubt that expert and tailored employment support is needed, this is not available at the moment and needs to be put into place even if these proposed changes don't happen.</p> <p>The proposed changes make it extremely likely that those that will be subject to increased work related conditions to obtain benefits will struggle to meet those requirements which are going to actually result in sanctions and reduce benefits so forcing people to undertake inappropriate work rated activities because they are frightened of losing their essential financial support.</p> <p>If these changes go ahead and Aspire's clients can't meet the new requirements they are going to be down over £4,600 income a year. This will lead to increased hardship and debt. Employment is good for people and we would love to see proper support available for those who can work, but that support isn't there. Stripping away financial help from people already disproportionately affected by the cost of living crisis is only going to create further problems.</p> <p>The chair invited people to ask questions in chat and moved to the next presentation.</p>
4	<p>Presentation from a NHS Nurse about pressure sores in non Caucasian skin types.</p> <p>The chair introduced Cerina to deliver her presentation, to raise awareness about Health inequality and the inequality in identifying pressure sores.</p> <p>According to the Office for National statistics in the last census within England the majority of those living in the country were white, with only 19% from black, Asian mixed or other ethnicities. Similarly in Wales with a population of over 3 million the majority are from white ethnicity. Nearly 94% of people living in Wales identify as having white ethnicity and 6.2% from a black, Asian or other ethnicity.</p>

There is a misconception that dark skin tones only relate to certain people from certain ethnicities but dark skin tones can present in anyone of any ethnicity, with certain ethnicities having permanently dark skin tones. Over the course of times beauty has changed from being really pale and not having any freckles being the epitome of beauty towards the more tanned you are the more attractive you are. This has led to people either artificially darkening their skin tone with sunbeds, fake tans or tanning injections. What people don't realise is by doing that you are altering your skin tone.

Pressure sores are defined by the National Office for Health Improvement and Disparities (formerly Public Health England) as a "localised area of damage to the skin or underlying tissues as a result of pressure". Pressure ulcers occur over bony prominences but can also be related to medical devices or other objects. With spinal cord injured patients this could be pressure either from sitting in a wheelchair too long or due to reduced mobility or reduced sensation. Evidence has shown that if your skin tone is dark you're more likely to develop a higher grade or pressure ulcer due to staff, relatives, caregivers or yourself being unable to recognise early skin deterioration.

Pressure ulcers cost the NHS £1.4m per day and they also have a negative impact on patients' mental health and wellbeing. If you've had a pressure ulcer, you are at increased risk of having another one; if you have a pressure ulcer in a healthcare setting it can add to your total length of stay by another four days. The older you get that prolonged length of stay increases up to about another 10 days more in hospital if you're over 75.

The Equality Act 2010 has certain protected characteristics like disability and race. The Equality Act prohibits the discrimination of certain groups either by the provision or lack of provision of a practice which is discriminatory in relation to a relevant protected characteristic or if it puts a certain group of people at a disadvantage.

Currently pressure ulcer care in the NHS is predominantly based and focused on light skin tone patients. Risk assessments look for indicators which primarily relate to light skin tone patients. Patients with a dark skin tone are at a disadvantage because there are no reminders to staff to look out for that because primarily they are instructed or encouraged to look for the redness of the skin.

With our health system as it is, the NHS having been founded 75 years ago and with an increase in people from countries where people have predominantly dark skin tones; it is only recently that certain trusts in England and Wales where individuals are raising this as an issue. Usually these individuals are of a dark skin tone and they've witnessed either themselves or their own relatives being disadvantaged due to the care they received.

Dark skin toned people are not recognised or represented on the risk assessment. A one size fits all approach is in place, decided nationally and used by all health boards so there is standardisation. When assessing somebody's skin the options available are moist, paper thin, dryness or blanchable redness that persists. Blanchable redness will only manifest on a light skin tone patient.

When pressure sores develop, at the first stage the skin hasn't broken and the pressure sore manifests as non-blanchable redness: this is a category one pressure ulcer. The skin hasn't broken down and there is a short window of time when it can be reeled backwards and prevent further damage. In dark skin tone patients that early damage is not recognised because staff are taught to look out for redness. Pressure damage is only noticed when the skin has broken or blistered: category two.

When the skin is broken it has a whole different implication. District nurses and dressings are required, bedrest might be called for. Looking at the example of a wheelchair user, they can't then sit in that particular position because it would be putting a lot of pressure on the broken skin, so they would need to go on bed rest. If they were working that takes them out of work and it has a ripple effect on a lot of other areas. Once it's a category two there's a higher risk that it'll develop into even more worse pressure ulcers.

	<p>If not everybody's skin goes red, pressure ulcer damage is going to be missed.</p> <p>We can work to embed a culture of recognition and respect of diversity. We can promote inclusivity in England and Wales, in our charities and third sector providers. Everyone was encouraged to look at their own material and see if it is inclusive and representing all members of the population they serve.</p> <p>A lot of spinal cord injured persons who are not in acute healthcare settings are living at home and either they're autonomous to their care or they have family or carers looking after them. Are they aware of the other signs of early pressure damage? Increasing that knowledge amongst individuals, health care staff, patients, families and caregivers so pressure ulcers can be caught before they develop.</p> <p>As much as reduced mobility, bowel and bladder incontinence and all other risk factors can contribute to pressure damage occurring; having a dark skin tone is also a very relevant risk because you are unlikely to see that early damage occurring, particularly if you've lost sensation.</p> <p>If make up producers can recognise that skin tones are different and produce different shades then care must recognize that people have different skin tones so damage will present in different ways.</p> <p>The Chair thanked Cerina for an impressive presentation that was well appreciated and pointed out the complimentary comments in the chat. He asked Cerina to put her email address into the chat so that people could email any questions directly.</p>
<p>5</p>	<p>SIA updates.</p> <p>The Chair introduced Dave Bracher Head of People SIA to speak about SIA updates and changes.</p> <p>Dave updated on some changes in the campaigns team at Spinal Injuries Association.</p> <p>The Parliamentary and Public Affairs Coordinator was promoted and moved into a management role at the Food Foundation in the summer and has been replaced by Glyn. Glyn is a former councillor and an army veteran and has been spinal cord injured since 2017. He was previously an Independent Living Advisor with Aspire, he joined SIA in August and is doing a tremendous job.</p> <p>Dave confirmed that he is moving internally at SIA and has been replaced as Campaigns Manager by Dharshana. She is very well versed in how Parliament works, having spent the best part of 20 years working across central government as a civil servant including a number of years working in Downing Street advising Prime Ministers. She has an unbelievable wealth of knowledge and her address book is honestly off the scale.</p> <p>As a charity, SIA are thrilled to have people of the calibre of Glyn and Dharshana joining.</p> <p>Dharshana thanked Dave for all the work he has done as the secretariat for the APPG and wider campaigning for the charity. She thanked all the presenters who had come to the meeting and expressed how she and Glyn were looking forward to working with the officers of the APPG and other parliamentarians in the coming months and years to look at the key issues affecting those with spinal cord injuries and to hopefully bring about systematic change.</p> <p>She then shared that Hudgell Solicitors and SIA will be joining together as campaign partner; a real boost for SIA and Dharshana stated that the charity are really looking forward to working together with Hudgell.</p> <p>The Chair thanked Dave on behalf of the All Party Group and wished him well for the future.</p>
<p>6</p>	<p>Any Other Business.</p> <p>With no other business, the Chair closed the meeting.</p>