

SMA UK Response to the Disability Action Plan

To what extent do you agree with proposals to review funding support and create an online hub to improve access to elected office for disabled people?

- Strongly agree

Any lengths to make the process of access to elected office is warmly welcomed. This needs to include access for the physically disabled. Access has already been improved with the introduction of virtual meetings, and the proposed measures to improve IT, which we hope will include software that works with voice recognition technology. However, people living with a disability should have the option to attend meetings in person, this is particularly important in a local government role where networking, honesty and transparency within the local community is essential. Therefore, it is crucial that government buildings from town halls to council offices are fully accessible for all, this would include installation of a Changing Rooms toilet facility wherever possible. Accessibility in public building needs to be reviewed by people living with a disability as many do not understand what is required for true accessibility for all.

To what extent do you agree with the proposal to create a hub of guidance about playground accessibility?

- Strongly agree

To what extent do you agree that the voluntary standards for playground accessibility should be made mandatory?

- Somewhat agree

A hub of guidance would be warmly welcomed. It is imperative that the DU works with a wide range of DPO's to create this hub. Accessibility varies enormously depending on the child and their condition. Physically disabled children need

equipment that they can play on independently - for example, a child who can not sit up independently and hold on to a swing may be able to lie in a net swing but can not get into it without a parent or carer lifting them, a wheelchair swing that the child can drive onto is far more accessible. However, we understand the financial implications of this and would not expect every new park to have one. The standards should have levels of expectation, possibly gold, silver and bronze standards . Bronze standard accessibility should be mandatory for new and refurbished parks which would include for example, sensory areas as well as step free access, enabling disabled children to explore with their peers would be the minimum expected requirement. Silver standard might include a range of supportive seating on swings and seesaws.. There should be at least one gold standard fully accessible park available in each council district and there should be some sort of incentive for developers to aspire to this standard.

If you know of existing guidance that the Disability Unit should consider including on the hub, please share them. You can include hyperlinks to information

Children's hospices would be a great place to go for advice, they have first hand experience of a range of childhood onset conditions, including rare diseases that are less known about, their play spaces are wonderfully tailored to meet a wide range of needs.

To what extent do you agree with the need to focus on the emerging area of climate adaptations and mitigations?

- Somewhat agree

Whilst we appreciate the need for clean air zones and are supportive of the principle, clean air zones round hospitals can negatively impact the lives of people who regularly attend outpatient appointments. Many hospitals across the UK are within clean air zones, especially tertiary centres. This makes driving to regular appointments very costly, there are many people regularly travelling to hospitals who do not qualify for Motability support. There should be an exemption code that comes with your hospital appointment.

To what extent do you agree that this scheme would give increased confidence to disabled customers when accessing businesses or services?

- Somewhat agree

Anything to raise awareness of disability and how it effects the everyday lives of so many people is, in essence a good idea. I would want to see people living with the disabilities that are being taught about,, and their representative organisations having a voice in the content of this training, being paid for their time and expertise. Many people living with physical disabilities like SMA just want to get on with living their lives, which includes step free access to shops, theatres and swimming pools, spaces they can manoeuvre a power chair around without causing any distraction and truly accessible changing and toilet facilities where appropriate.

To what extent do you agree that access to assistive technology would be improved by better-informed advice from public sector staff?

- Somewhat agree

Assistive technology can significantly increase an individual's quality of life, as you say the cost is the biggest barrier to access. It would be great to see the government subsidising the costs as well as educating public sector staff as this would have a greater impact.

We would like to see an experienced user of assistive tech in the champion role.

Wellbeing and opportunities for disabled children

The Disability Unit (DU) is proposing establishing a task force to improve the wellbeing and opportunities of disabled children.

This task force would bring multiple government departments together to work on a broad issue that they are all responsible for in different ways. It would aim to improve the way government services for disabled children work together.

The proposed areas of focus would be: transitions to adulthood, accessibility of public spaces and transport, bullying, personal safety and the impact on wellbeing and early identification of need and support for families.

To what extent do you agree with each of the following proposed areas of focus?
Transitions to adulthood

- Strongly agree

Accessibility of public spaces and transport

- Strongly agree

Bullying, personal safety and impact on wellbeing

- Strongly agree

Earlier identification of need and support for families

- Strongly agree

If there are other issues that you think this taskforce should consider, or you would like to explain your answer, please do so here.

Ensuring the Equality act is being followed for children living with disabilities, by examining the equity of care provision, reasonable adaptations and inclusion for children with physical disabilities and complex medical needs within a mainstream school setting across the UK, including early years settings.

What do you think of the plans and suggested areas of action described in this consultation as a whole? Are these the right things for the government to be focusing on over the next year?

There is much to do before England is even close to being 'The world's most accessible country'. SMA UK have collected opinions from the community on this topic:

'I struggle to get a push-chair around England, let alone my daughter in her wheelchair. Playgrounds are not accessible, schools lack accessibility, it's fight after fight to get my daughter into education suited to her; mainstream school (physical disability only). Education is everybody's right - yet because accessibility is poor disabled children are treated unjustly, it should not be a fight to get your child into mainstream school.'

'Funding and EHCP reports have been stripped back or refused, my child doesn't qualify because she is cognitively fine, yet very physically disabled (needs 1 to 1 care) but isn't entitled due to the EHCP report being ineligible, it's not fair at all.'
'Public toilets are not accessible and poorly maintained. Streets and some shops are inaccessible.'

1- Many places (both public and private) are still ignorantly behind and provide poor for disabled access needs such as shops, public transport such as tube stations etc.

2- The threshold for a public place of work to provide a disabled toilet is too high and many places do not provide one.

3- Traveling on planes and trains for those with zero independent mobility is still challenging when it comes transfer from a wheelchair onto a normal chair and the toilet sizes are inadequate.

4- There is a general shortage of taxis for disabled people who cannot make independent transfers and have to stay on their chairs throughout the journey.

5- Many disabled people rely on their dogs for emotional support and unfortunately other than guide dogs, one cannot access many places with a dog for emotional support.

6- Disabled people are discriminated by the high cost of any item related to disability including those to help with access such as ramps and also other items such as those recommended by OT and other exercises despite the Vat exemption. One reason is that it is generally assumed that such items are provided by either NHS or charities whereas in majority of cases one has to purchase them privately.'

'Children under 3 with disabilities need to be able to have more accessibility to disabilities help. For example, babies under 3 who have been diagnosed with SMA are unable to claim the Mobility part of Disability Living Allowance, which means they are unable to apply for the Mobility Scheme and get access to a mobility vehicle. Yes they are babies and still small but they have medical equipment that they need to take with them, also specialised buggies to support their posture and usually don't fit in a standard car boot. Specialised chairs and standing frames that they may need to transport to other family household or childcare places.

Also there is not enough support, especially financial support for working parents who's child has been diagnosed with a disability e.g. SMA and they are unable to work as they need to take care of their child or they need to have time off work until they adjust to their child's disability and make all the necessary arrangements for their child to be cared for whilst they work and the company will not pay them so it's unpaid time off and very stressful time for the parents.'

'We are a long way off, too many businesses, shops, restaurants not accessible, toilets in accessible or locked or used as store rooms. Train travel, have to book assistance gap between train and platform too big. Wheelchair user or walking with a disability couldn't use London underground. Gyms, health clubs swimming pools no access or set up for wheelchair users.'

'Well England has a long way to go before that statement becomes true!

1- we still can not go everywhere without a great deal of pre planning as there are many public buildings as well as private homes that are not wheelchair accessible.

2- I can't believe that in this day and age we still struggle to find a wheelchair accessible taxi in Cheshire and when we do eventually find one, we are charged 3 times the price! Most taxi companies will advertise that they do have wheelchair accessible taxis but when you come to actually book one there are normally non available. This is discrimination.'

'Up the pay for the carers to about £15 per hour and £20 at weekends because it is getting harder to find good carers on the rate of pay.'

'The disability act back in 2001 was meant to improve access problems. But failed because of lack of penalties . Let's hope this will not be repeated.'

'I feel like the most basic things are missing before even looking into more detail. My son is 8 and I have never been able to take him to the park he is a full time wheelchair user and cannot access anything. As he cannot self propel easily the only sport he can easily access is powered wheelchair football but to participate in this the chairs are nearly £9000 and to compete you have to have a vehicle able to transport it. Swimming lessons at school although mandatory there is no adjustments made to incorporate wheelchair users. There is no help for PE teachers to include them in lessons. Many children have to miss so many hours of school due to appointments and illness and yet there is no easily accessible way to catch up on missed work.'

'Access to regular physio at home. Prompt access to medical specialists. Prompt, knowledgeable and relevant attention by Wheelchair Services. Suitable access to ALL public buildings, to include shops and railway stations. Better availability and funded access to wheelchair taxis, especially for power wheelchair users. which could be paid for by local authorities. More consideration and nationwide provision for adults with ALL disabilities, physical and mental/emotional. A single specialist point of contact/co-ordinator for SMA patients, with prompt response. Improved access to air travel and to safety of equipment that is needed by the patient.'

What alternative actions might the government consider that would make a positive difference to the lives of disabled people?

- Continue to improve accessibility of public transport - including accessible taxis
- Support and benefits for families with newly diagnosed children under 5.
- Increased pay for PA's /carers.
- Increase the number of changing places toilets across the UK.
- Incentives to make public places and shops and leisure facilities step free.
- Increase the percentage of accessible social housing.

- Improve the system for children living with disabilities in a mainstream school setting.

Throughout this action plan, the important role of the voice of those living with disabilities has been recognised. Organisations representing those people living with disabilities have much work to do, sharing information, collecting opinions and responding to the government. If the government value this work, they will need to financially support these organisations, especially at a time where the cost of living crisis means charities are struggling.