Contributor’s MP

16th November 2021

**RE: Mr Simon Smith, Appendix to letter dated 30th July 2021**

Dear [Contributor’s MP] and colleagues,

At the request of your office, I have produced the summary document below indicating the areas in which Mr Simon Smith would like the MP’s office to take action to influence national policy and local delivery relevant to people with Autism Spectrum Conditions (ASC) and Attention Deficit Hyperactivity Disorder (ADHD). You have already received a comprehensive letter in which the issues experienced by Simon are used to evidence common themes in the experience of adults with ASC and ADHD, and this document should be considered in conjunction with that letter. To confirm, in that letter, we requested:

* [Contributor’s MP] to be a champion of awareness of neurodiversity
* Pressure to be applied by the MP’s office on local leaders to progress the development of an ASC/ADHD pathway that is fit for purpose
* Sharing of this letter with relevant Parliamentary colleagues
* Dedicated work to drive forward the ambition of the Autism Act (2009) and Equality Act (2010), including adaptations to the legislation if necessary, to ensure equality for people with neurodiversity
* Support for reform of the welfare benefits system to align it with other national priorities, and to ensure it is respectful of people with disabilities, particularly those with neurodiversity

Key focus points for your consideration:

1. **Challenges of implementing national Autism Strategy:** Although the Autism Act (2009) creates specific expectations related to delivery of care, treatment and support for people with Autism, with particular focus on guidance to local authorities, this often falls short of the Act’s stipulations. This is something that the National Autistic Society have campaigned about rigorously and more details can be found here at this [link](https://www.autism.org.uk/what-we-do/campaign/not-enough/about-the-autism-act). We ask for your support in ensuring [*“The national strategy for autistic children, young people and adults: 2021-2026”*](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf) becomes a reality. In particular, Simon’s case indicates the need for commitment to:
	* Chapter 3 – improving understanding and acceptance of autism within society
	* Chapter 5 – supporting more autistic people in to employment
	* Chapter 6 – tackling health and care inequalities for autistic people

Simon’s experience indicates that there will be multiple barriers to achieving these outcomes, due to the structures of society and public service, and the lack of autism awareness amongst professionals and the wider public. Simon would ask that you give consideration to your scope to assist in the removal of these barriers, including but not limited to:

* + **Limited access to Legal Aid to challenge poor application of legislation relevant to people with ASC** – Simon has been told repeatedly that he needs to take legal action to escalate his case against the local authority and NHS regarding omissions in his care. He has only recently been able to secure legal advice regarding improper use of the Care Act after many years of searching for representation, but cannot secure legal advice related to inequalities issues. Tackling unequal access to health and care, and improper use of the legislation in place to protect the wellbeing of people with ASC is essential but impossible for those on limited incomes.
	+ **Limited care offer for adults with ASC and ADHD** – constituents living in [contributor’s constituency] receive an exceptionally limited care specialist care offer for these conditions. Simon’s experience tells an extensive story about constant and repeat interaction with multiple agencies to try to source the clinical, psychological and social support that diagnosing clinicians have clearly stated he needs. Without appropriate interventions, it seems unlikely that residents of [contributor’s constituency] who are neurodiverse will be able to access opportunities to better their life, gain meaningful employment, and will continue to experience significant inequality in terms of their health and wellbeing.
	+ **Routine reassessment of needs in line with welfare benefits checks, when ASC and ADHD are lifelong, developmental disorders** – processes for assessing someone’s welfare benefit entitlements are intensive, require significant investment of time, and can be very distressing; for Simon, this is often the cause of extreme distress in advance of an assessment, when assessment paperwork arrives, when seeking clinical and professional evidence, when being reassessed and whilst waiting to receive the outcome. This happens once every 18months and attributed distress can last around 6months. Although there are times when Simon experiences less distress, his ASC and ADHD are permanent conditions for which he cannot receive appropriate care. The disability benefits review processes convey a systemic lack of understanding of the nature of ASC, the life changing impact it has on someone’s ability to work.
	+ **Poor or lacking understanding and awareness of ASC and ADHD** – this lack of understanding is present in all of society, not just in health and social care. Our society is designed to favour those who are neurotypical, meaning that neurodiverse individuals often find themselves misunderstood, confused or ill-equipped to manage. This has the potential to make job searching, dating, shopping, complaining, volunteering, etc… more difficult for people with ASC and ADHD. Neurodiverse individuals do not get to live their life to their full potential. Without a greater awareness across our populations, changes are often made to services and how they communicate without any consideration given to the impact on those who are neurodiverse. Government policy should not be signed off without specific consideration being given to the impact of that on people with disabilities, and as such, those who are neurodiverse.
	+ **Inaccessible complaints procedures for public sector organisations and bodies** – if services are to become more responsive to the needs of people with ASC and ADHD, then they need to enable people with those conditions to share their feedback and experience. Simon has been involved with a programme of work delivered by NHS England, [Ask, Listen, Do](https://www.england.nhs.uk/learning-disabilities/about/ask-listen-do/people-information/), which is a suite of tools designed to improve complaints processes to make them more accessible for neurodiverse people and those with learning disabilities. Across the Board of public service, complaint making needs to be accessible to all, and championing initiatives such as Ask, Listen, Do helps to progress ambitions around awareness and equality of access. The Department of Health and Social Care has committed to using the Ask, Listen, Do principles, and yet people such as Simon still experience challenges with being heard.

Simon has been involved in several campaigns with the National Autistic Society, and has been maintaining a close focus on the work of the All-Party Parliamentary Group on Autism, previously chaired by Dame Cheryl Gillan, who avidly championed people with ASC taking responsibility for getting their local MP involved in debates and discussions on ASC at a national level. Simon takes his role as a champion very seriously and wishes to encourage your commitment to work on ASC.

1. **Encourage more stringent enforcement of existing Acts and legislation**

The Equality Act (2010) makes many stipulations around ensuring that those groups facing disadvantage due to their protected characteristics are more extensively assisted to overcome any barriers. In particular, the Act mandates the implementation of reasonable adjustments for people with disabilities. In Simon’s experience, he has struggled enormously with public and private sector organisations who fail to comply with the requirement to make reasonable adjustments. This appears to be a significant challenge faced by neurodiverse people, who are often asking for adjustments that are not standard. For example, it is commonplace to be able to request a meeting room with wheelchair access, but far less easy to arrange for a meeting room with adjustable lighting, where the temperature can be closely managed, and the noise level controlled. In addition to that, a particular problem faced by Simon is that he needs people to adapt their methods of communication which often they seem unable to do. However, there appears to be no consequence for agencies failing in this regard. Again, without the support of legal aid to address equalities issues, how can ineffective implementation of legislation be challenged?

Simon seeks your assistance in ensuring that policy decisions in government are considered through the lens of how they impact neurodiverse people, and people with other disabilities and long-term conditions. Simon continues to give his time to giving voice to the issues of neurodiverse people, and has been involved in several campaigns, some celebrated by politicians in the Houses of Parliament, and yet the change is not apparent.

1. **Importance of understanding the needs of neurodiverse people in new Social Care legislation**

Following the publication of [Build Back Better – Our Plan for Health and Social Care](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1015736/Build_Back_Better-_Our_Plan_for_Health_and_Social_Care.pdf) in September 2021, it is apparent that work is pending to adapt the legislation governing the delivery of social care. It is critically important for the future of social care that any proposed plans specifically indicate clear requirements around the provision of social care for people with social support needs due to neurodiversity, and that necessary resource is provided to local authorities to enable this.

The needs of people with ASC and ADHD do not fit neatly in to a standard social care offer; they do not necessarily have a learning disability, nor do they have a mental health condition, which are typical social care departments. Instead, they are likely to have specialist health, psychological and social care needs, and any social care legislation needs to account for the interlocked way in which this care should be provided by local services.

Simon is keenly aware of work that is taking place, led by [Inclusion London](https://www.inclusionlondon.org.uk/home-page-blocks/social-care-charging-campaigning-resources/), challenging care charging in social care. In [contributor’s constituency], this is a key concern for Accessible [contributor’s constituency] Disability Access Forum. Where needs of individuals cannot be met through social care, and yet there is a requirement for their financial contribution to this incomplete picture, this can leave people with disabilities financially challenged and with ongoing, assessed, but unaddressed needs. For people with ASC and ADHD, with a multitude of needs, some of which require clinical intervention, and others which are social, the current funding arrangements are poorly connected and leave huge gaps in available support.

1. **Local service change**

Simon has approached yourself on many occasions to make requests regarding your support to influence local change. As indicated in our letter of 30th July 2021, there are significant gaps in commissioned services for people with ASC and ADHD in [contributor’s constituency]. Simon has raised these issues with [contributor’s constituency] Clinical Commissioning Group, [contributor’s constituency] Council, NHS England, [contributor’s constituency]Partnership Foundation Trust, General Practice, all of whom acknowledge there is a “commissioning monster” for joined up care for people with ASC and ADHD, but who state they are powerless to influence this from their positions. When Simon contacted the Department of Health and Social Care to raise these concerns, he was told to seek the support of his local MP, and as such, we are asking for your assistance.

There is no expectation from Simon that you will have the answer to the commissioning issues, but your authority and your endorsement of the need for change for local residents could be a powerful influence in addressing the ongoing challenges for people with ASC and ADHD of seeking support for their conditions and finding it isn’t there or is incomplete and being told “there’s nothing that can be done.”

I hope this is a useful summary of the requests that Simon is making for your assistance. In our initial letter, we asked that you share the content of Simon’s letter with several MPs to ensure maximum reach and influence. Simon’s story is complex and challenging; he wishes that learning from his experience can be utilised to improve the lived experience of neurodiverse individuals. I have updated the list of MPs with whom we ask that this content is shared:

* The Rt Hon Boris Johnson MP, Prime Minister
* Chloe Smith MP, Minister for Disabled People, Health and Work
* The Rt Hon Sajid Javid MP, Secretary of State for Health and Social Care
* Edward Argar MP, Minister for Health
* Maggie Throup MP, Minister for Vaccines and Public Health
* Maria Caulfield MP, Minister for Patient Safety and Primary Care
* Gillian Keegan MP, Minister for Care and Mental Health
* The Rt Hon Michael Gove MP, Secretary of State for Levelling Up, Housing and Communities
* The Rt Hon Therese Coffey MP, Secretary of State for Work and Pensions

We look forward to meeting with you to discuss these issues and any further actions to be undertaken on 17th November.

Kind regards

HH

Chief Executive, Healthwatch [contributor’s constituency]