Dear Ms Greenwood,

Thank you for your letter of 20 March about the Driver and Vehicle Licensing Agency (DVLA)’s guidance for drivers with autism spectrum disorders (ASD).

It may help if I explain that there was previously an inconsistency in the advice being provided. The guidance to medical professionals advised that all applicants and driving licence holders with an ASD must notify the DVLA. However, our A-Z guide for the general public advised that only those whose ASD had an impact on their driving must notify us.

On 15 February we changed the online guidance for the general public to address this inconsistency. Unfortunately, this caused confusion and we are genuinely sorry for any concern that was caused. The online advice for both drivers and medical professionals now makes clear that drivers with an ASD only need to tell the DVLA if their condition could affect their driving.

We recognise that advances in medical knowledge are rapidly improving the understanding and treatment of medical conditions and we keep all our processes under review. Driver licensing is a complex matter and the DVLA frequently seeks the advice of medical experts. We also have a regular forum with medical charities representing the various patient groups. There are now 19 charities which are members of that forum. We have invited the National Autistic Society to join that forum.

The overarching medical standards for driving are in part based on both UK and European law, which underpins everything we do relating to driver licensing decisions. The standards for, for example, diabetes mellitus, epilepsy and vision are set in law but others are formulated using advice from the six honorary medical advisory panels to the Secretary of State. The panels focus on the conditions that impact on safe driving and are made up of nationally and internationally renowned experts in specific fields, to ensure a good balance of expertise.
In answer to your specific questions:

1. **How many and what proportion of licence holders have an autism spectrum disorder that affects their ability to drive?**

   The DVLA maintains a register of over 48 million driving licence holders. Of these, 5,986 have Asperger’s syndrome and 4,561 have autism noted on their driver record. However, many of these drivers have notified us of at least one other medical condition so we are unable to say whether the ASD specifically affects their ability to drive.

2. **How many drivers have been fined for not telling DVLA about (a) a medical condition and (b) an autism spectrum disorder that affects driving?**

   The police are responsible for taking forward prosecutions of drivers who have not fulfilled their legal obligation to notify the DVLA of a medical condition. The DVLA records details of any endorsements imposed by the courts as a result of any such prosecutions for four years, and they are then removed as required by law. In the last four years, five drivers have had an endorsement placed on their records by the courts for not telling the DVLA about a medical condition that could affect their driving. However, we do not hold information about the details of the condition involved as the information is provided to DVLA without reference to a specific medical condition. As a result, it is not possible to say if any of the endorsements relate to non-disclosure of ASD.

3. **In how many road traffic accidents a driver’s autism spectrum disorder was found to be a contributory factor?**

   While the government publishes statistics around road traffic accidents and general driver illness and disability, these do not include information about whether an ASD was specifically a contributory factor in any accidents.

4. **What guidance was changed? And why did the DVLA decide it was necessary to change the guidance?**

   The DVLA provides two sets of guidance on medical conditions that may affect someone’s ability to drive and these align with each other. The first, “Assessing fitness to drive”¹, is intended to assist doctors and other healthcare professionals in advising their patients whether the DVLA needs to be notified of a medical condition and what the licensing outcome from the DVLA’s medical enquiries might be. The other set of guidance is aimed at the general public and is called “A-Z guidance”².

   There was an inconsistency in the advice being given, with the advice to medical professionals stating that all applicants and licence holders with an ASD must notify the DVLA, while the A-Z guide advised only those whose ASD impacts their driving to notify us. However, our attempts to align and clarify the guidance caused confusion and concern.

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² [https://www.gov.uk/health-conditions-and-driving](https://www.gov.uk/health-conditions-and-driving)
Further discussion with our doctors resulted in the decision to align both to only require drivers with ASD to notify us if their condition affects their driving.

5. **What was the process for, and who was involved in, approving changes to the guidance?**

The guidance for drivers with medical conditions is formulated in conjunction with the relevant honorary advisory medical panel. In this instance, the issue of the inconsistent advice on the two sets of official guidance was discussed on two occasions with the relevant panel. There was general agreement at the most recent meeting, held in March that the current advice is correct and balances the needs of individuals with that of road safety.

6. **Did the DVLA consult anyone about the proposed changes?**

Our intention in this case was to address an inconsistency in the two sets of guidance rather than change policy. Our standard approach to changes to legislation and policy in this area is to work collaboratively with the relevant panels and key stakeholders. The change in February 2019 to the guidance for group one drivers with diabetes treated with insulin is an example of this. Before making changes to our guidance, we consult with key organisations including medical experts, road safety and industry groups. For diabetes this included the Association of British Diabetologists, Diabetes UK, the Independent Diabetes Trust, the Royal Society for the Prevention of Accidents, BRAKE, the Road Haulage Association and the Freight Transport Association.

7. **Does the DVLA seek any advice on its communications with groups of people that have particular needs?**

We aim to engage as fully as possible with stakeholders and charities when formulating advice directed at groups of people with particular needs. Our regular charities forum seeks views on our services from charities and patient groups. We also utilise our User Experience Laboratory which allows us to trial new communications and services with the people who are most likely to use them. I accept however that we could engage more with certain groups, and going forward we will be looking to work more closely with the National Autistic Society to help us tailor our communications for drivers with ASD. My team has already been working with the National Autistic Society, in particular around exploring if a functional checklist for drivers to help determine when they may need to declare their diagnosis to us would be helpful.

8. **Has the DVLA conducted an equality impact assessment of either its guidance or its communications relating to its guidance?**

We did not carry out a specific equality analysis assessment as our intention was to correct an inconsistency across two sets of guidance. However, we will certainly learn lessons from this incident and look to improve how we communicate with groups with more specific needs.

9. **How does the DVLA justify describing the changes to its guidance as having ‘muddied the waters’? And was any assessment made of the difficulty people with autism spectrum disorders may have had understanding the meaning of this idiom?**
I fully recognise that the phrase you have highlighted was unhelpful and that our understanding of ASD and the language we used in our communications on social media, could have been improved. We are taking steps to ensure that the language we use in all of our communications is appropriate for the intended audience. In relation to ASD, we will be looking to work with the neuro-divergent public sector group to ensure that our literature is as clear as possible and meets our customers’ specific needs.

10. How many people or groups have contacted the DVLA about this issue since the guidance was first changed? How is the DVLA dealing with this correspondence and what account is being taken of people’s communication needs when responding to the guidance? When does the DVLA expect to have dealt with all outstanding correspondence?

Around 250 people were potentially affected during the period where the advice was for those with ASD to notify us of their condition. We have written to drivers asking them whether their condition affects their driving. The letter for these drivers was reviewed and cleared by a member of the neuro-divergent public sector group who is based in the DVLA to ensure that it was as clear as possible. We are dealing with all responses as a priority and only if a person advises that their ASD affects their driving will medical investigations be undertaken. To date, 171 drivers have confirmed that their condition does not affect their driving and have retained their licences with no further action required.

We have also been contacted by the National Autistic Society and the Royal College of General Practitioners about this issue.

11. What other disorders of this kind are covered by DVLA guidance and are there any plans to change such guidance?

Our guidance covers other pervasive development disorders including attention deficit hyperactivity disorder and severe communication disorders. We will continue to work with the medical panels, stakeholders and charities to ensure our understanding of these conditions as well as how we communicate with customers with these conditions. In particular, we are considering whether the names of the conditions used in our guidance are still appropriate and whether there is a need for any of the conditions to be listed in a separate section with more tailored advice. We will, of course, ensure that we consult with stakeholders and relevant charities before making any changes to the guidance.

12. Does the DVLA now hold any information about drivers with an autism spectrum disorder or related disorders for drivers where the disorder does not affect the person’s ability to drive? Does the DVLA hold consent to obtain medical records for any driver whose disorder does not affect their ability to drive? And what does the DVLA plan to do with such information?

Notifications of ASD received during this period where the driver has subsequently confirmed that the condition does not affect their driving will not be stored on the driver record and any unnecessary medical questionnaires will be destroyed. Any consent to obtain medical records in these cases will not be retained and no further medical investigations will take place. However, we have informed customers that we will retain their confirmation that their ASD does not affect their driving on our case management records to show why we have not
made further medical investigations and why we accessed the driver record to remove the ASD notification.

I hope this is helpful, but please let me know if you need any further information.

Yours sincerely,

[Signature]

Julie Lennard
Chief Executive