

Submitted to **1. Summary survey**

Submitted on **2019-11-01 10:13:43**

1. What Scotland needs to do

1 What do you think about the ideas in this section?

I like the ideas

Why do you think that?:

The National Autistic Society Scotland fully supports the suggestion that Scotland's mental health law needs to change for autistic people and people with learning disability. We agree that the law needs to change to comply with the United Nations Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights in full. We welcome the work completed by the review this far and applaud the principle behind the proposals. We support a number of the proposals brought forward and would like to use this survey to highlight areas where we believe improvements could be made or aspects must be reconsidered.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

We would favour a more detailed approach in which it is clearly and explicitly stated how the proposals in this review will achieve this compliance, with reference made to the relevant rights and conventions throughout.

2. How we understand autism, learning disability and mental health

1 What do you think about the ideas in this section?

I have mixed feelings about the ideas

Why do you think that?:

We fully support a move away from regarding autism and learning disability as 'mental disorders'. However, we have concerns over the language and definitions being proposed by the review in relation to autism.

Autistic people refer to themselves in many ways, with different terms being more popular than others. However, there is a growing number of people on the autism spectrum who reject the term "impairment" when

used in relation to their autism in any way, and we believe that a number of autistic people would be hostile to this suggestion. Autistic people tend to see their autism as something which makes them experience the world differently from neurotypical individuals, and any resulting impairment is caused by external factors within a world that is not yet autism-friendly rather than the autism. We would be strongly opposed to the proposition of a new definition in law which refers to autism as 'autistic impairment'.

Additionally, we have some concerns over the suggestion that autism can cause a 'temporary autistic disability'. Again, this seems to imply that it is a person's autism which is the cause of any temporary stress, distress or serious limitations when, in reality, it is external, sensory and societal factors which will always be the source in these circumstances. We believe that moves towards a definition which gives the impression of autism 'flaring up' or having 'peaks and troughs' could not only prove to be misleading, but could also hinder knowledge of what autism actually is.

We are concerned that providing professionals with an option to simply 'diagnose' any mental health crises experienced by an autistic person as a temporary result of their autism is a problematic step that could lead to lazy diagnosis and the opposite of what is intended.

As stated, we fully support a move away from the 'mental disorder' label, but it should not be replaced by a definition that has its own set of problems and dangers.

In terms of capacity, we believe that everybody should be treated equally, meaning someone with autism and/or a learning disability should be treated the same as someone without, with the same safeguards and processes in place. Someone's autism should be considered as a contributing factor in relation to capacity, but not the defining factor.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

The term 'autistic impairment' should be reconsidered as it is a problematic proposition that will almost certainly be met with opposition by autistic people in Scotland who reject the term 'impairment' in relation to their neurodivergence. We would support use of the simple term

'autism', with more emphasis placed on ensuring that professionals and the wider public are fully aware of and understand what autism is and what it means for autistic people.

Additionally, we would support a greater emphasis being placed on the external and societal factors which lead to 'temporary autistic disability', and what can be done to improve those, rather than equating stress, distress and limitations to an individual's autism.

Further clarity is also required in relation to capacity. The autism spectrum is varied to such an extent that no two autistic people are the same, and while one autistic person may have full capacity when it comes to decision-making, there has to be acceptance that others may not.

3. Support for decision making

1 What do you think about the ideas in this section?

I have mixed feelings about the ideas

Why do you think that?:

Families, carers both paid and unpaid play a vital role in supporting people with complex needs and their views are invaluable in making informed decision about care and support.

Families often tell us that their views and input is ignored and interventions are dictated by professionals and budget restraints. This can lead to people being placed in inappropriate provision with inadequate support leading to crisis.

We therefore welcome the enhanced role for 'decision supporters' and unpaid carers.

However, more clarity is needed in this section, on safeguards which would be put in place to ensure that the best interests of the individual are central to the process and that views of third parties in no way act to undermine that.

We are happy with the proposal of replacing the advance statement in the Mental Health Act with a statement of rights, will and preferences. However, we feel there could be more clarity given in the proposals as to how this statement would be compiled (in particular who is obligated to

coordinate input from the individual, advocate, decision supporters and unpaid carers and produce the final version).

Furthermore, what would the process be in situations where a person is unable to give such a statement, does not have an unpaid carer prepared to contribute, and does not have a suitable independent advocate.

In addition, although we support more powers and a greater role in decision making for independent advocates, we fear that not enough consideration has been given to the lack of access to efficient independent advocacy in certain parts of Scotland. Like other areas of the proposals, this is an aspect which does not seem to take geography or funding into consideration.

We further welcome the proposal that duties be placed on Scottish Government and public authorities to fully fund independent advocacy so that those who need it can access it effectively.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

There should be greater detail provided on proposals such as the creation of a rights, will and preferences statement, and how greater reliance on independent advocacy would work and would be both sustainable and accessible.

4. Support, care and treatment

1 What do you think about the ideas in this section?

I have mixed feelings about the ideas

Why do you think that?:

Like other sections, we fully support the good intentions of the proposals but find the lack of clarity problematic. For example, the biggest issue facing autistic people in Scotland is a lack of services in all areas, including mental health – an issue which is even worse for those living in more rural or isolated locations.

We believe that autistic people should not only have rights in law to have access to the support, care and treatment that they need, but that they

should also have accessible, efficient, convenient support, care and treatment available to them.

In terms of improvements in support, care and treatment provided for women, children and offenders, we would contest the explicit suggestion that women simply need better access to diagnosis. Our position is that all autistic people require better access to diagnosis across Scotland. The biggest barrier faced by autistic women is, in fact, a lack of awareness, knowledge, and understanding with regards to autism, which results in a belief that autism is a male condition. We would argue, therefore, that this is not necessarily an access-to-diagnosis problem but, instead, an awareness issue and would fully support any attempts to improve this situation.

Additionally, we welcome the proposals to ensure that autistic children and children with a learning disability have a right to be offered a Co-ordinated Support Plan. However, we know from the experiences of autistic children and their parents that Co-ordinated Support Plans are currently not achieving a high success rate and, therefore, would suggest the proposals could go further in suggesting improvements to CSPs.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

While understanding the main aim of the review is to ensure the rights of autistic people and people with learning disabilities are protected in law, we do feel more emphasis should be placed on the quality, accessibility and efficiency of the specific support, care and treatment available. We would argue that having the legal right to access services which are poor or largely non-existent is essentially a minor, trivial step forward and would, therefore, expect more in the way of detailed proposals including steps to overcome barriers such as geography and resourcing.

5. Where support, care and treatment happens

1 What do you think about the ideas in this section?

I have mixed feelings about the ideas

Why do you think that?:

We strongly support the idea of community support and welcome the proposals around this. We also support the suggestion that Scotland should move from a medical model to the disability model.

We welcome the principles behind safe places and secure support centres, but do have some concerns and questions as a result by the review's suggestions.

We support the idea of safe spaces being introduced in Scotland, and would highlight the 'crash pads' in Durham as an effective example of this, but believe far more fleshing out of the idea is required. Geography remains a factor that appears to have been neglected by the review and far more clarity is required on how many safe spaces would be introduced throughout Scotland and how accessible these would be to people in rural areas – for example, would the intention be for there to be one safe space per local authority?

There also appears to be a lack of detail on the resourcing and sustainability of these safe spaces, in particular whether their introduction would take resources from other services and/or lead to a situation where quantity is favoured over quality. Additionally, there does not seem to be any assurance or accountability measure proposed to ensure that Health and Social Care Partnerships follow through with implementing safe spaces as expected.

We would also suggest that the idea of safe spaces is re-evaluated, taking into consideration services which have already proven to provide effective support to autistic people in local areas such as One Stop Shops.

We find similar concerns are raised by the proposals around secure support centres. The idea of specialist, support centres for autistic people and people with learning disability is welcome in principle, however, there appears to be lack of any real concrete proposals to achieving that goal and issues similar to those with the safe space proposals exist.

We fully support the proposals to make general hospitals and psychiatric hospitals accessible for autistic people and people with learning disability, as should be the case with all services in Scotland. We believe that it is far more constructive to target mental health services across Scotland that work for all, including those with autism, rather than

proposals which involve the building and resourcing of separate services. This would be far more sustainable.

We welcome the suggestion that 'standards should be set' in secure support centres to allay the fear that these services would essentially become new ATUs. However, we believe that far more clarity should be provided on what these standards should look like, and what the underlying purpose of these centres would be – for example, temporary detention while community treatment is found or a long-term treatment solution.

We appreciate the idea of a national autism service but remain unconvinced it is the correct way forward. We believe that a number of the duties expected of such a service could be undertaken by the Mental Welfare Commission, and would support the assigning of any further duties to a newly established 'Autism Commissioner', rather than a service involving a broad range of professionals, which we believe would be more effective and more sustainable. Such a position could also have a remit covering areas outwith mental health, such as education and the criminal justice system. We believe that autistic people need and deserve a joined up system is required that covers all areas of service provision in Scotland, not simply mental health.

Additionally, we find the name 'national autism service' to be misleading, as it suggests a service for autistic people across Scotland rather than an advice and information provider for professionals, and would urge reconsideration of this.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

We believe more consideration must be given to the proposals of both safe spaces and secure support hospitals in order to provide more detail on what these would look like, where they would be located, how accessible they would be to those outwith urban areas, and how sustainable they would be likely to be.

These proposals could also be bettered by taking into consideration the effectiveness of the One Stop Shops, which has proven massively popular and successful within Scotland's autistic community.

Additionally, we believe the idea of a national autism service would be made better first and foremost by a reconsideration of the title. However, we would argue that the intended objective would be better achieved by duties undertaken by the Mental Welfare Commission and a newly established 'Autism Commissioner', rather than a new 'national autism service'.

6. How professionals make decisions

1 What do you think about the ideas in this section?

I do not like the ideas

Why do you think that?:

We have serious concerns over the suggestion that 'Scotland is not yet ready to end all detention on the basis of disability, or all compulsory treatment, in a safe way'.

We acknowledge the review's concerns regarding suicide. However, we would argue that anyone detained because of a mental health crisis or possibility of suicide is being detained on the basis of those particular reasons, whether or not they have autism, and, therefore, should be considered separately. Our charity believes strongly that no-one should be detained on the basis of disability and will continue to make this case.

We also firmly disagree with compulsory treatment for similar reasons. Autistic people in Scotland deserve a solution that aims to fix the support and societal factors that may cause a mental health crisis, rather than receiving compulsory treatment on the basis of their autism.

We would urge reconsideration of this suggestion. There is a clear difference between an autistic person detained on the basis of a mental health crisis, and an autistic person detained on the basis of their disability. The former can be justified, the latter cannot.

We will continue to speak out on this matter and may have no alternative but to challenge this suggestion if it is ultimately recommended to the Scottish Government.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

The review should acknowledge that no-one should be detained on the basis of their disability and should make suggestions accordingly.

7. How decisions are monitored

1 What do you think about the ideas in this section?

I like the ideas

Why do you think that?:

We fully support ideas in this section.

2 Could these ideas be made better?

No

How could these ideas be made better?:

8. Offenders

1 What do you think about the ideas in this section?

I like the ideas

Why do you think that?:

We fully support ideas in this section.

2 Could these ideas be made better?

No

How could these ideas be made better?:

9. Where support, care and treatment happens for offenders

1 What do you think about the ideas in this section?

I like the ideas

Why do you think that?:

We fully support the suggestions regarding support, care and treatment for offenders, and would just place further emphasis on the clear fact that placing an autistic person in a non-adapted cell is an attack on their human rights.

2 Could these ideas be made better?

No

How could these ideas be made better?:

10. What this means for the law

1 What do you think about the ideas in this section?

I have mixed feelings about the ideas

Why do you think that?:

As stated previously, we support a move away from the 'mental disorders' definition but have concerns over the new proposed terms and definitions.

We also support a new law to give 'positive rights' for support, care and treatment but believe further additions are crucial, such as the aforementioned Autism Commissioner role or even a separate Autism Act to enshrine autistic people's human rights and ensure accessibility to services.

In terms of Scotland ending detention on the basis of disability, we have made our position clear on this. We are further concerned by the lack of timeframe for achieving this, other than 'some time in the future'.

2 Could these ideas be made better?

Yes

How could these ideas be made better?:

The suggestion of 'autistic impairment' as a definition should be reconsidered, as should the assertion that Scotland will only be prepared to end detention on the basis of disability 'some time in the future'. Further consideration should also be giving to the establishment of an Autism Commissioner and potentially autism-specific legislation.

About you

1 What is your name?

Name:

Jason Henderson

2 Are you taking part as an individual person, as a professional or as a group of people?

A Group

3 Do any of these apply to you?

None of the above

4 If you are taking part as a professional, what is your profession?

Profession:

5 If you are taking part as a group, what is the name of your group?

name of group:

National Autistic Society Scotland

6 Do you live in Scotland?

Yes

7 Do you want us to publish your response?

Yes please publish my response anonymously

If you want to say anything else at all please say it here: