

Paper 2 for the Care and Treatment Advisory Group meeting on 21st June 2018

The title of Paper 2 is **Plans for Stage 1**

This paper will be discussed in the second session, after the break.

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Notes:

- These papers are written in Plain English but they are not Easy Read
- If there is something in the papers that is not clear please tell us
- If you are a volunteer you can tell Catherine about this at your support meeting
- Advisors are not expected to give advice about all sections. If there is a section which you think does not apply to you, you do not have to think of a comment or response.

A. Where the Review is at now

Advisory groups have been set up.

Some *ad hoc* advisors have agreed to give advice when the Executive needs this from them.

Scottish Government has approved the Review's budget for this year, from April 2018 to March 2019.

The Mental Welfare Commission has agreed that the Review is carrying out work that fits with the Commission's responsibilities.

This means that it is legally right for the Review to seek, store and report on all of the evidence that it needs for the Review.

Simon (Secretary) and Catherine (Project Manager) are starting to spend the Review's budget on the things that we need so that we can involve people in the Review and get evidence for the Review.

We have been contacted by the team for the Review of the Mental Health Act in England and Wales. Andy and Simon will speak with the Chair of that Review.

Do you have any questions or comments about progress on the review?

B. Some things that we need to think about for our evidence

Children

The 2003 Act gives some specific rights to children.

Children also have additional rights under the United Nations Convention on the Rights of the Child.

We want to understand the experiences of autistic children and children with learning disability who receive care and treatment.

Only a small number of children are subject to the 2003 Act at any time.

Many more children receive care and treatment, and we need to know whether there are any particular issues for children.

We are thinking of having a meeting with some people to give us advice on how to engage with children.

Women

The United Nations Convention on the Rights of **Persons with Disabilities** tells us to give specific attention to children, and also to women.

The 2003 Act has a section on equality, but does not specifically mention women as a group of people.

We need advice about how to run the Review so that it is inclusive for autistic women and women with learning disability.

Carers

The 2003 Act gives some specific rights to carers.

We want to understand the experiences of carers.

We need carers' views on how well the 2003 Act promotes and protects the right to mental health for autistic people and people with learning disability.

We are thinking of meeting with some carers and carers organisations to get advice on how to engage with carers.

Disabled People's Organisations

The CRPD says **how** Scotland should develop laws and what those laws should address.

The CRPD says the Review has to engage with organisations *of* people with disabilities.

In Scotland, those include:

- organisations run *by* autistic people – such as ARGH and AMASE – and
- organisations run *by* people with learning disability – such as People First.

Do you have any questions, comments or suggestions about engaging with:

- **children,**
- **women,**
- **carers or**
- **Disabled People's Organisations?**

C. Evidence for the Review

Evidence means any information that can help us to make recommendations to the Minister for Mental Health.

Overall, we are seeking evidence on how well the 2003 Act promotes and protects the right to mental health for autistic people and people with learning disability.

All evidence will be compared against international human rights standards.

Examples of where evidence will come from

Here are some examples of different types of evidence:

- Reports from people who have had compulsory care and treatment under the 2003 Act about their experiences
- Reports from professionals who have used the 2003 Act. This would be about how the Act promotes and protects the right to mental health.
- Information from legal experts about laws in other countries. We want to hear from countries that are trying to comply with same human rights requirements as Scotland.

Evidence about the law

Some of the evidence that we seek on the law will have to come from expert lawyers. This is because the Review is mainly interested in whether the 2003 Act promotes and protects the right to mental health.

The 2003 Act is complex. Also some concepts about human rights can be difficult to understand.

However, we want to explain human rights and the 2003 Act to people in a way that most people can understand.

We expect that some people will be able to understand their right to mental health.

If people understand their right to mental health we will ask them directly whether they think their right to mental health was promoted and protected.

Some people will only want to talk about their experiences. That is fine. When that happens the Review team will work out what those experiences tell us about whether the person's human rights were promoted and protected.

Evidence we are not going to seek

The Review will not seek evidence on causes of autism or learning disability.

The Review will consider evidence about a range of approaches to providing medical treatment, care and support. But the Review will not look into why different types of treatment, care and support work well or do not work well.

Do you have any questions or comments about the evidence we are seeking in general?

D. The evidence we will seek at Stage 1

By the end of Stage 1, we will have evidence of **people's experiences of the 2003 Act**.

This section describes our plans to seek evidence at Stage 1.

The 2003 Act mainly applies to compulsory care and treatment, including how decisions on this are made, monitored and reviewed.

Lived experience of the 2003 Act

We will seek evidence from people with learning disability and autistic people who have been 'subject' to the 2003 Act. That means that they have experienced compulsory care and treatment.

We will ask about their experience of any aspect of their care and treatment that they want to tell us about.

We will be particularly interested in their experience of:

- Care and treatment to promote and protect mental health
- Being prescribed psychotropic medications. This is any medicine for mental health.
- Psychology
- Mental health and the criminal justice system.

These topics are part of the remit for the Review.

Autistic people and people with learning disability who have not experienced compulsory care and treatment

The Act also applies to some people who have not experienced compulsory care and treatment.

For example, the Act gives a right of access to independent advocacy to all people with 'mental disorder'.

We may seek evidence from those people also.

Carers and professionals

We will seek evidence from carers about the experiences of the people that they care for.

We will seek evidence from professionals about their experiences of the 2003 Act.

We will seek all of this evidence to help us understand how well the 2003 Act promotes and protects the right to mental health.

How we will seek evidence

A separate paper, 'The Review's Human Rights Based Approach', describes how we will apply a human rights based approach to this Review using the PANEL principles.

Under 'participation' the table says we plan to 'Involve people with lived experience of all levels of ability'.

We want to have evidence from autistic people and people with learning disability who have a whole range of communication abilities.

Other information in that paper gives examples of *how* we plan to gather evidence.

The paper also uses the FAIR process to describe:

- What evidence we want to seek
- How we plan to seek that evidence
- How we plan to analyse that evidence

The Communication and Engagement Group will work on the detail of how we seek evidence.

What evidence do you think we should be looking for in Stage 1?

This should be evidence that tells us whether the 2003 Act is effective in promoting or protecting the right to mental health.

Where do you think we will find that evidence?

This could be from organisations, from experts, or recorded information such as guidance or research, for example.

E. How we will work with the evidence that we get

At the end of Stage 1, we will write a report that says –

- What evidence we have received
- What evidence we did not receive

We will report on this evidence in relation to human rights.

We will be most interested in what the evidence tells us about how well the 2003 Act promotes and protects the rights to mental health for autistic people and people with learning disability.

An example of how we will work with evidence across the Review

An example of how we will work with evidence across the three stages of the review is **on the next page**.

Because this is the Care and Treatment group, this example is about **psychotropic medications**. This means any medicine for mental health.

We will begin each stage by making arrangements for people to participate in the Review.

Do you have any questions or comments about how we will work with evidence across stages of the Review?

Stage 1 – what happens now?

We will look at what international human rights law says about how psychotropic medication for mental health **should** be provided to autistic people and people with learning disability. We may then look for other sources of information about this.



Then we will seek evidence of how psychotropic medication **is** provided in Scotland now.

We will assess whether psychotropic medication is being prescribed in a way that promotes and protects the right to mental health.



Stage 2 – what could happen differently?

We will look for evidence of **other approaches** to prescribing psychotropic medications that protect and promote the right to mental health.

For example we may look at **England's** new approach to prescribing psychotropic medication for people with a learning disability.

We will be interested in what **laws** are needed to make sure that prescribing practices promote and protect the right to mental health for autistic people and people with learning disability.



We will work with **people with lived experience, people who understand the law, and other professionals.**

They will help us to decide if we think the law should change or not.



Stage 3 – what we think should happen

In Stage 3, we will put our findings out for **consultation**. That consultation will be open to anyone who wants to respond to it.

After the consultation, we will make our **recommendations** to the Minister for Mental Health.

F. The second meeting of this group, and the Review's timescales

The second meeting of the advisory groups

The **second meeting** of this group will be different.

It will take place in October 2018. This will be during the time when we expect to be collecting evidence for Stage 1.

All four advisory groups will be invited to that meeting. People can sit in their own groups, but all be in the same room.

The purpose of the meeting will be to update people and to discuss ideas.

There will be Session 1, a break, then Session 2.

Session 1:

In session 1 we will:

- Tell people our progress on collecting evidence for Stage 1
- Tell people about any further advice we need for Stage 1.

People will have the opportunity to talk about what they have heard, in their groups, and then each group can speak in turn to everyone else.

Session 2:

In session 2, we will tell people what our ideas are for Stage 2.

People will have the opportunity to talk about what they have heard, in their groups, and then each group can speak in turn to everyone else.

Timescales

Here are the **timescales** that we are currently planning for the Review:

Months	Stage	Tasks for the Review	Advisory group meetings
June to August 2018		Developing tools, testing approach	First meeting Training (optional)
September to November 2018	Stage 1	Consultation	Second meeting
December 2018 to January 2019	Stage 1	Analysis and reporting	Third meeting
February 2019		Developing tools	
March to May 2019	Stage 2	Consultation	Fourth meeting
June to July 2019	Stage 2	Analysis and reporting	Fifth meeting
July to August 2019		Developing tools	
August to November 2019	Stage 3	Consultation, analysis and reporting	
December 2019		Report to Minister	Sixth meeting

Do you have any suggestions about what we should do at the second meeting?

Do you have any questions or comments about our timescales?

Annex 1: Advice from the scoping study on what evidence the Review should seek

This text has been copied and pasted from 'Views on the scope of the Review'. It is not in Plain English.

The full scoping study report can be found here:

<http://www.gov.scot/Resource/0051/00512868.pdf>.

An easy read version of the report is also available from Catherine.

The experiences of people who have been detained

3.8 People thought that it was crucial that the review explore in detail the experiences of people with learning disabilities and autism who have been detained under the 2003 Act. Interviewees suggested that the review should gather evidence about a representative sample of these cases to ascertain:

- The factors leading to their detention in hospital
- Whether they could be cared for in some (less restrictive) way without the use of compulsion, and if so, why they continue to be cared for in hospital
- What exactly is being done for these individuals while they are detained in hospital (i.e. what is the nature of any assessment, care or treatment they receive and who provides it)
- The purpose of any medication used in the care and treatment of these individuals
- The assessment by the Mental Health Tribunal of the justifications for a compulsory treatment order
- Whether these individuals have been offered, and have made use of, independent advocacy services or other types of support to communicate their views.

3.9 It was suggested that a case study approach would be appropriate to gather this evidence. It was also thought that this evidence collection could be extended to include individuals with learning disabilities or autism who have **previously** been detained under the 2003 Act (since it came into effect), but are no longer in hospital. Outcomes for these individuals should be identified.

3.10 One interviewee referred to research currently being carried by an international team led by Dr Eilionóir Flynn at the National University of Ireland (NUI) Galway. The VOICES project (Voices of Individuals: Collectively Exploring Self-determination) is investigating how the use of supported decision-making might work in practice in relation to: (i) consent to medical treatment; (ii) criminal responsibility; (iii) contractual capacity; and (iv) consent to relationships / sex. The study has significant involvement from people with disabilities. It was suggested that this research may not only provide an important source of evidence for the review, but may also offer lessons in how to involve people who have been subject to the 2003 Act in the review process....

Learning disability and autism in the criminal justice system

3.11 One of the reasons given in the Millan report for including learning disability in the 2003 Act was that it would allow people with learning disabilities and autism who commit offences to be detained in hospital rather than sent to prison. However, interview and survey participants in this scoping study noted that the 2003 Act is not being used for this purpose in a consistent way. Concerns were voiced about the high proportion of people in prison in Scotland who have a learning disability or autism. These individuals were seen to be at very high risk of being bullied, harassed and exploited in prison.

3.12 In contrast to this view, learning disability groups commented that being detained under the 2003 Act was „worse than being in prison“ since, if a person with learning disability is put in prison for breaking the law, at least that person will get out again whereas if that person is detained under the Mental Health Act, they may be detained for a far longer period of time, and have greater restrictions placed on them than other people who commit more serious offences. It was suggested that the length and nature of restrictions placed on people with learning disabilities seem to be out of proportion to the offence committed.

3.13 Different participants suggested that the review should gather evidence about:

- The reasons that people with learning disabilities and autism come in contact with the criminal justice system
- How the criminal justice system deals with these individuals (at arrest, in court, in prison) – specifically, the extent to which

supported decision-making is being promoted in criminal justice contexts, and the provision of the 'Appropriate Adult' scheme in particular

- The long term outcomes for people with learning disabilities and autism who have been in contact with the criminal justice system since the 2003 Act came into force
- Whether people with learning disabilities and autism are disadvantaged in the criminal justice system as compared to other people
- The supports available to help people address their behaviour before it becomes a criminal justice matter.

3.14 There were also calls for the review to look at the application of the 2003 Act in forensic contexts. People thought the review should answer the following questions:

- Are people with learning disabilities and autism being disadvantaged (for example, compared to people with a mental illness who do not have a learning disability) when they are detained in hospital through criminal justice processes?
- What is the nature and purpose of the care and treatment these individuals receive when they are detained in a secure hospital?

3.15 It was suggested that there may be differences between people's experiences in relation to civil and criminal proceedings, and that the review should consider both. In addition, there was a concern that people with learning disabilities and autism may find it much harder than other people to seek justice when they have been the victims of an offence.

The experiences of other jurisdictions

3.16 People agreed that the review should gather evidence about legislative arrangements in other countries relating to people with learning disabilities and autism, and there was particular interest in new legislation recently enacted in Northern Ireland. People also wanted the review to consider the experience of New Zealand which has separate legislation related to learning disability.

Others suggested that the review should gather evidence from:

- England and Wales where a 2007 amendment of the Mental Capacity Act 2005 resulted in the development of 'Deprivation of Liberty Safeguards'
- Germany where it was reported that 'everyone has the right to be heard in court, even if they have impaired mental capacity'
- British Columbia in Canada where there was reported to be legislation about supported decision-making
- Scandinavia which was seen to have a more progressive criminal justice system
- Relevant human rights-related court judgements in other countries.

Review of learning disability and autism in the Mental Health (Scotland) Act 2003: Findings from a scoping exercise. Scottish Government, December 2016.

<http://www.gov.scot/Resource/0051/00512868.pdf>