



The independent review of
**Learning Disability
and Autism**
in the Mental Health Act

Notes from Advisory Group meetings

Third meetings

29th January to 7th February 2019

Stirling and Perth

Who was there	Law and Policy	Care and Treatment	Criminal Justice and Mental Health	Communication and Engagement
Who was there from the review	Andrew Rome Simon Webster	Andrew Rome Simon Webster	Andrew Rome Simon Webster	Catherine Evans Simon Webster
Advisors who were there	Experiences of people who do not communicate with speech Learning disability Human rights based approaches International human rights law	Autism Learning disability Psychology	Autism (two advisors) Learning disability Nursing Prison Psychiatry	Autism Intellectual disability Experiences of people who do not communicate with speech Advocacy Engagement
Advisors who couldn't make it	Autism (comments) Scottish Mental Health Law	Experiences of people who do not communicate with speech (comments) Psychiatry Social Work		Engagement – Advisor has had to withdraw from the group
Supporters	No	Yes	Yes	No

Advisors' comments on paper 1: Draft outcomes

What the advisors thought about using outcomes for mental health law

<p>Law and policy group</p>	<p>The group was very positive about this approach.</p> <p>Some people may wonder how we will measure these outcomes.</p> <p>It would be good to have 'accountable' in the outcomes – there is no accountability in some section of the Mental Health Act (for example, on Local Authority duties). Accountability is part of a human rights based approach.</p> <p>The draft is very good and comprehensive, and the terms broad enough to catch a wide net of issues, without losing their focus.</p>
<p>Care and treatment group</p>	<p>This practical outcomes approach is a good one, against a human rights framework that we have agreed is a good one. We need to make sure that outcomes are not so broad that they are woolly.</p> <p>The approach helps give clarity and sets a benchmark. The outcome are easy to follow and very detailed. A weakness of this approach can be that not all situations are covered in each outcome, people don't always fall clearly in to one particular area due to the complexity of their condition.</p>
<p>Criminal justice and mental health group</p>	<p>The group was generally happy with the outcomes approach</p> <p>Chair's comment – the main outcome for criminal justice has been changed to: 'Criminal justice is fair and helpful for the person'</p>
<p>Communication and engagement group</p>	<p>An outcomes approach is good. It's good that the outcomes have lists of points. This gives something to focus on and aim for.</p> <p>Throughout, we need to check that everything is worded as an outcome, not as an output</p>

X. The law promotes and protects all of the person’s human rights

What the advisors thought about this section, in general

<p>Law and policy group</p>	<p>Human rights give people rights of access to care and treatment by giving ‘positive duties’ to governments. So there is a need for an outcome (or outcomes) about making sure that people have the care and treatment that they need.</p> <p>We need to think about whether the law can do anything to ensure quality in care and treatment, and what the law can do (for example, guidance, training, codes of practice, monitoring)</p>
<p>Care and treatment group</p>	<p>This section may need to recognise that disabled people are people first and foremost</p>
<p>Criminal justice and mental health group</p>	<p>The outcomes need to address public safety.</p>
<p>Communication and engagement group</p>	<p>Elsewhere, one of the outcomes is “professionals relate to people as equals and use their authority in a fair way” - this is a good outcome but it should apply across the whole of the Act</p> <p>Think about rephrasing sentences to put ‘person’ first wherever possible. This would fit more with the way that language is used elsewhere – person centred – and people would not have to think in two different ways.</p> <p>We can’t assume that people know what their human rights are so they can make an informed choice on whether they feel that their rights are being met – we may need an outcome on this.</p> <p>The outcomes are written as if they are statements of fact – that might be confusing for some people. WE could use a different tense – instead of ‘are’, we could use ‘will be’ or ‘is doing.’</p>

What the advisors thought about some outcomes

X.3	Scotland's mental health law requires decisions that respect the rights, will and preferences of persons with disabilities instead of decisions about people's best interests	Law and policy group	<p>The first half of this outcome is generally supported by all who work in human rights. The second part is more contentious.</p> <p>Sometimes decisions have to be made for a person, but its needs to be proved that this decision incorporates the rights will and preferences of the person.</p> <p>One way of doing that is make decisions based on a best interpretation of what the person would want, when their will and preferences cannot be known clearly, instead of making decisions about what is in their best interests.</p>
		Care and treatment group	<p><u>Respect</u> is the right word but can be woolly: how do you make it meaningful in practice?</p> <p>Does it need to say, respect AND incorporate?</p> <p>People should be able to ask someone (maybe a parent) to limit what they do when they are not well.</p> <p>If people are trying to tell you that you can't do something, they should have to explain themselves.</p> <p>There are some people with a very severe learning disability who are not in a place where we can say they are giving their agreement based on their ability to understand the purpose of treatment – but it can always be possible to engage with people to understand what does and doesn't work for them</p> <p>Everyone knows what they want even if they can't say it</p>

		Criminal justice and mental health group	<p>Need to carefully consider how this would work with people who cannot make their own decisions or communicate their own views; including whether or how advance statements can be made for this group of people</p> <p>Need to consider situations where people may adversely affect their own rights, through the choices that they make</p>
X.5	Scotland's mental health law leads to the end of people being treated without their agreement because they have a disability	Law and policy group	<p>The test of whether the law is discriminating is whether we would we make the same decision for that person if they didn't have a diagnosis. If not, that's discrimination.</p> <p>Rights are equally true for everyone – but rights are not applied equally for everyone, as if you have a diagnosis your decision is more likely to be questioned.</p> <p>This is a particularly good outcome – a 'stretch goal'</p>
		Care and treatment group	<p>This is more controversial – it does make sense but people may have to read it more than once to get it. It may need to be worded differently.</p>
		Criminal justice group	<p>Sometimes people with disability will need to be treated without their agreement</p> <p>Mental health law's main purpose is to make it possible for people to be given care and treatment that they need when they are unable to decide to accept this care and treatment.</p> <p>This outcome is needed, partly because people with learning disability are detained in hospital for much longer than other groups, because there is often no support to move back into the community</p>

X.6	Scotland's mental health law prevents all care, treatment and support that may be cruel, inhuman or degrading treatment	Criminal justice group	This outcome might not be needed because of outcome X.9 below: The law in Scotland ensures that absolute rights are always protected
X. 7	The law in Scotland ensures that all services for persons with disabilities are monitored independently and effectively, and that professionals meet their duties and act within their authority	Law and policy group	This is a good outcome for accountability, which is required in a human rights based approach
X.8	The law in Scotland ensures the right to living independently and being included in the community	Law and policy group	This needs to be a right for the person to live in their community
		Criminal justice group	People who are detained because of crime could not have an absolute right to live in the community This outcomes is needed, for example, to make sure that autistic people are not 'dumped' in psychiatric wards

A. People are safe in a crisis

What the advisors thought about this section, in general

Law and policy group	It would be good to have 'accountable' in the outcomes – there is no accountability in some section of the Mental Health Act (for example, on Local Authority duties). Accountability is part of a human rights based approach.
Care and treatment group	Sometimes people's involvement with the criminal justice system is a sign that they are in crisis

What the advisors thought about some outcomes

A.1	Suicide risk is recognised in individuals and is acted upon	Care and Treatment group	Needs to address the fact that autistic people and people with learning disability may present differently when at risk of suicide
		Criminal Justice and Mental Health group	There needs to be needs be scope in the legislation to help the person through the crisis situation, collaboratively
A.2	Assessments are done well to prevent crisis	Care and Treatment group	'done well' – a measure could be that the individual feels protected and free, so the assessment has worked This needs to be an outcome – it's worded as an output Assessments that are done by professionals who don't know a person can make a crisis worse (eg – an intermediary may be needed for communication)
		Criminal Justice and Mental Health group	Needs to be more specific – in case people are thinking about assessments for – for example – self directed support

A.3	All individuals have their support co-ordinated effectively	Criminal Justice and Mental Health group	The person needs to have a lead role and to be checked up on. The person should be able to make the decision where he wants to help – a lead role in assessment, support
A.4	Care is well planned, to prevent crisis	Criminal Justice and Mental Health group	To measure this outcome there would need to be a baseline to identify minimum set of criteria on what people need to achieve re care planning
A.5	Specialist care is provided, to prevent crisis	Criminal Justice and Mental Health group	Prevention is important The legislation needs to give people the ability to manage the crisis
A.7	People have the support that they need when very distressed	Criminal Justice and Mental Health group	Bringing someone with autism into hospital in crisis may make things worse: a complete change of scene, then kicked out again. A place of sanctuary would be appropriate in certain situations
A.8	People have effective support to get through a crisis when living with family or in the community	Care and treatment group	A person may not be distressed but may need support, and may pose a risk to others. The context is all around the individual being safe. Some people (for example) with autism may need support but not be distressed People may be displaying behaviour that is resulting from their stress, that then distresses other people
		Communication and Engagement Group	..or in wards or in prison. May be better just as 'people have effective support to get through a crisis'

B. All decisions promote and protect the person’s human rights

What the advisors thought about this section, in general

Law and policy group	These outcomes are very good and are very clearly expressed.
Criminal justice and mental health group	Public safety also needs to be reflected in outcomes; rights need to be balanced with serious risk to others. There are service provision issues – treatment support and meaningful activities are needed to prevent re-offending

What the advisors thought about some outcomes

B.1	All decisions are based on people’s rights, will and preferences	Law and policy group	See comments in section X on rights, will and preferences
		Criminal justice and mental health group	Suggestion of ‘respect’ instead of ‘based’ on, in the context for criminal justice – presumption could be to follow preferences, but not in some circumstances
B.2	People have fair opportunities to challenge professionals	Criminal justice and mental health group	Assistance will be needed for this

B.3	Decisions on physical restraint prevent assault or death, and prevent unnecessary restraint or seclusion.	Law and policy group	Outcomes are needed on restraint: There is a lot of controversy around the use of physical restraint and compliance training in the Autistic community. It is often used on children. Physical contact for those on the autistic spectrum is highly difficult and emotive due to issues surrounding physical hypersensitivity and over stimulation. It can be very hard to understand that physical restraint really must be an act of last resort. It can very easily just exacerbate a situation where an autistic is struggling to communicate their distress and what may be causing it. Physical restraint for those on the spectrum can turn into physical abuse and assault, and can leave lasting trauma and PTSD.
		Care and Treatment group	Physical restraint should also be associated with very strong review processes involving the person themselves whenever possible. A firm approach may occasionally be the least restrictive approach that is acceptable to the person (for example, for some autistic people). Some people would want , restraint to be last resort – for example, – only if are going to hurt the person that is trying to help you
		Criminal justice and mental health group	This would need monitoring
		Communication and Engagement Group	This might be better separated out, as two points. It may need to be reworded along with the outcome on seclusion
B.4	Opportunities are provided so that the least restrictive option is available for each person	Criminal justice and mental health group	People should have an element of choice in how behaviour is managed for the protection of staff, patients, and the person

B.6	People can return to their home area from other areas if they want to	Care and Treatment group	Care also needs to be provided as close to communities as possible – not moving too far away from home
B.8	People can choose to use seclusion, but are only put into seclusion if there is a clearly identified and significant risk of serious harm to others that cannot be managed with greater safety by any other means	Law and policy group	It's not very good for the person to get put in a room
		Care and Treatment group	For some people, having a space to go does not mean the same as seclusion We need to check whether seclusion is acceptable by human right standards
		Criminal justice and mental health group	For choice – we could say ‘having access to quiet relaxing place’ but not seclusion. Seclusion means a locked door for de-escalation. When planning care – some people prefer seclusion to restraint or medication. We do need to act in ways that keep people safe.
		Communication and engagement group	People should not feel that they need to be locked in a room to feel safe. A person may want a bit of privacy, instead of using the term seclusion Seclusion is not just in hospital – it could be in a care home. Some people may choose to live in seclusion

B.9	Carers are involved in everything that they should be involved in	Communication and engagement group	<p>This is about decisions and may need to be split into two points – one about people who are able to choose to have their carers involved in decisions(or not) – and one about people who can't make that choice, whose carers can share knowledge of the person's will, preferences and communication.</p> <p>Also, it may be siblings who have this knowledge at times.</p> <p>There is also an inconsistency, where a guardian under Adults with Incapacity does not have the same role under the Mental Health Act.</p> <p>There are also people such as friends who have a level of connection with the person.</p>
-----	---	------------------------------------	--

C. Medicine has a positive effect for the person

What the advisors thought about some outcomes

C.1	Psychotropic medicine is not prescribed 'off label' unless absolutely necessary	Law and policy group	We need to explain what need to explain what 'off label' is
		Care and treatment group	There is a need for an outcome about promoting active reduction of historical levels of medication – down to the minimum level of medication required 'absolutely necessary' would need to be defined. Any medication that is given should be for a diagnosed illness, not to control behaviour
		Communication and engagement group	We need to explain what need to explain what 'off label' is Under the law at present, it's possible for everyone in one service to be prescribed the same medication – 'just in case'
C.2	Psychotropic medicine is not given to people under compulsion unless absolutely necessary	Care and treatment group	This needs to be explicit about who makes that decision and how it is made. This might need to include covert medication. For example - psychotropic medication is not given covertly or under compulsion unless absolutely necessary. If it is, people don't know about side effects or information

C.3	Other care and treatment is always given to people before psychotropic medication is given under compulsion	Law and Policy group	<p>There needs to be a positive duty in law for this outcome.</p> <p>Where a person presents significant a risk to others, there is a need to explore different therapeutic opportunities before medications are used, but choice of care and treatment may need to be reduced for that person</p>
		Communication and engagement group	<p>There is a need to explore safeguards in relation to other forms of care and treatment</p>
C.4	People are not prescribed psychotropic medicines when they have concerns about adverse effects	Criminal justice and mental health group	<p>There are some current safeguards, including second opinion doctors.</p> <p>Sometimes, people may not want medication as they believe that they don't need it, but medically, they do need it.</p> <p>Discussion included situations where people have serious concerns about serious adverse effects, or where people chose not to take medication and accept the consequences of this for their health.</p>

D. Care and treatment have positive effects for the person

What the advisors thought about the outcomes, in general

Law and policy group	There needs to be something about maintaining levels of good physical and mental health and wellbeing. This should be general principle and could go elsewhere, but it may be most relevant here
Care and treatment group	The individual is still an individual in a crisis. Rights will and preferences should be taken into account in a crisis (for example, beliefs)
Communication and engagement group	The issue of coercion is important and needs to be considered too. We may need something specific on accessibility, and on knowledge of rights. For example, all information should be made available to people about care and treatment, and professionals should not be withholding information from them. For example, advance statements have to be accessible for the person.

What the advisors thought about some outcomes

D.1	Autistic people and people with learning disability are understood and feel accepted by services	Communication and engagement group	This needs to be not just about mental health services, but about health services in general Outcome needs to include that the person understands
D.2	All professionals have the skills that they need to support people well	Criminal justice and mental health group	For autism: Skills – this is a major problem. Not that staff aren't interested – they are keen to learn – they are just not given adequate training.

D.4	The rights support is available for behaviour challenges	Care and treatment group	Seclusion, restraint and medication for behaviour challenges are not care or treatment for the causes of behaviours
D.5	Mental health services are accessible for autistic people and people with learning disability	Care and treatment group	We may need to explain what we mean by accessible (for example, for people needs, or in time, or in distance)
D.6	All adults with autism have access to good diagnosis and assessment	Care and treatment group	Fine as an outcome for autism; but few women and few people from BME groups are getting diagnosis, and access varies across the country Need to add in – adults with learning disability (a source was suggested source for this outcome)

D.8	Children with autism or learning disability have the mental health services that they need	Law and Policy group	..in their communities
		Criminal Justice and Mental Health group	There is a need to regain expertise in nursing for children in this area – this was lost when children’s hospitals closed and services moved to social care
D.11	All environments for care and treatment promote and protect all human rights	Law and Policy group	This could include the right to continue private and family life as much as possible, no matter where the person is
		Criminal Justice and Mental Health group	We may need something in the law to make sure that when people are compelled to be treated, this has to be in environments that meet their needs. This may be about the physical environment, and about it being as close to home as possible. Sending consultants up to an area can be much more cost effective as a model for providing services

E. Criminal justice is fair and helpful for the person

What the advisors thought about the outcomes, in general

Criminal justice and mental health group	<p>The framework may need an outcome about public safety – about protecting other people from the risk of serious harm. This might refer to people who do not understand the offences that they have committed. It might also be about people not being put in a position where they commit more offences.</p> <p>Outcomes needs to be about offenders but also about witnesses and victims with autism or learning disability</p> <p>Outcomes also need to be about specialist services</p>
--	--

What the advisors thought about some outcomes

E.1	Autistic offenders and offenders with learning disability are diagnosed – if they want to be – and are supported	Law and Policy group	..throughout the criminal justice system
		Care and Treatment group	..throughout the criminal justice system Difficult, as criminal justice services may think you are trying to ‘dodge the system’ if your needs are not known – they might think you are pretending that you don’t understand things
		Criminal Justice and Mental Health group	‘if they want to be’ At present, court process can assess that you are not fit to stand trial. People might not want to have a label or the consequences of a label, but if they don’t get a diagnosis they may not get help and assistance The trial process would be fundamentally unfair if a person went through trial without a diagnosis Some people may not have the capacity to make a decision on whether or not to get a diagnosis Some people need information to be put in certain way – so a person would not know how to speak to person with autism if they didn’t know that the person had autism or didn’t understand autism A professional may believe that a person with autism does not understand the court process, when they do understand the court process. A professional may believe that a person with learning disability does understand the court process, when they do not understand the court process. Diagnosis needs to lead to better support care and help. Some people have been screened in prison and there has been no difference in health care

E.3	Disabled persons are not restricted more than any other person who presents the same risk	Law and Policy group	For example, the use of indefinite sentences can be unequal. You have to be able to get out somehow even if that means having a particular form of support at the end of the same sentence. We need to apply the same criteria whatever route people have come into the criminal justice system by.
		Criminal Justice and Mental Health group	Yes to this outcome. This is partly about how risk is assessed.
E.6	Women are placed in appropriate services	Criminal Justice and Mental Health group	The outcome needs to be about parity and equality in service provision Many professionals don't know or understand how autism presents in females
E.7	Trials take place for everyone who wants one and each person has the adjustments that they need for their trial	Care and Treatment group	Everyone should have a fair trial Is this about not having a psychiatrist determine whether a person stands trial?
E.8	People have the representation that they need	Law and Policy group	This needs to be more specific – for example, is it about access to legal aid?

E.9	Autistic people and people with learning disability can receive the same sentences as other people, with adjustments made to fit their needs	Law and Policy group	Check the wording of this, to make it easy to understand – ‘fit their needs’: address or take account of their needs? The concept of people being able to be in prison with adjustments is correct for people’s human rights
-----	--	----------------------	---

Advisors' comments on Paper 2 - Proposal for stage 2 engagement

<p>Law and policy group</p>	<p>Advisors thought that the plan was sensible and coherent</p> <p>There were some suggestions of organisations and individual experts for the review to meet with</p> <p>About autism: There is a need for targeted feedback, but there is the possibility of sections of the community feeling unheard, or spoken for. Autistic led organisations are the main source/point of contact. The timescale is a bit tight, but other than that the plan looks very good, with each stage leading logically from the preceding one.</p>
<p>Care and treatment group</p>	<p>The plan covers all individuals who may have experience and be able to participate. It covers a wide variety which is a fair approach and will help the review get to where they want to be.</p> <p>It's important to set out a best case scenario with an acknowledgement that it may take time to achieve it.</p> <p>The outcomes framework is very accessible.</p> <p>A plan based on outcomes like this will need to have 'staging posts' – people need to have routes to creating change.</p> <p>The structure for stage 2 is pretty good. It would be better to meet with more than one Health & Social Care Partnership as they are so different</p>
<p>Communication and engagement group</p>	<p>We could involve a lawyer who is an expert on welfare rights.</p> <p>Be aware of learning disability week, to avoid clashes – from around the 12th May</p> <p>Other organisations were suggested for stage 2, that are led by people with lived experience.</p> <p>We may get a better idea of people's experience of being in the community under the Mental Health Act, by going through organisations that provide support in the community</p>