



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

Final consultation

Stage 3 of the review

Plain English survey

Short version

August 2019

The contents of this survey

This survey gives you a very short summary of each part of the consultation document for this stage of the review.

You can see the whole consultation document [here](#).

If you want to respond to any section of this survey in detail, we suggest that you get the full survey for that section.

You can get the survey document for each section of this consultation [here](#).

You might want to respond to a section or sections of the survey online. To do this, click on this [link](#).

If you need help with this survey, you can call email us at

irmha.scot@nhs.net

or you can phone us at

0131 313 8744

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1. What Scotland needs to do

We think that Scotland's mental health law needs to change for autistic people and people with learning disability.

We think that the law needs to change to comply with the United Nations Convention on the Rights of Persons with Disabilities.

We also think that it needs to change to comply with the European Convention on Human Rights in full.

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

| | |
|-------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- Recommendation 4.6 of the New Directions Report (Millan, 2001) for 'an expert review at an early date of the position of learning disability within mental health law' (p. 36) was not completed.
- Millan proposed following the example of New Zealand in creating specific legislation to provide for the rights of people with 'intellectual disability' separate from mental health provisions.
- The recommendation to place learning disability and autistic spectrum disorders within the 2003 Mental Health Act was to be temporary and subject to review so we support the proposal to use the UNCRPD and ECHR as a framework for establishing new legislation.
- As a profession based in healthcare we support the move away from a medical to a social and human rights based model.
- We also note that in ICD 11 (World Health Organization) autism and learning disability are sub-classified along with speech and language disorders under neurodevelopmental disorders, distinct from mental and behavioural disorders.
- This distinction should support the proposal to remove autism and learning disability from the definition of mental disorder.

3. Could these ideas be made better?

| | |
|-------------------------------------|--------------|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |
| <input type="checkbox"/> | I don't know |

4. How could these ideas be made better?

- The Review may wish to consider the fact that there are many more people living in Scotland who have communication difficulties and adopt a more general but inclusive legal definition referring to difficulties with communication.
- This could avoid potential criticism that new legislation is discriminatory against other groups.

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

We suggest that Scotland needs to move to understanding autism and learning disability as disabilities, not as mental disorders.

We think that Scotland's mental health services for autistic people and people with learning disability need to move to a human rights culture.

In Scots law, everyone is presumed to have legal capacity. We suggest that it should not be possible to challenge the legal capacity of autistic people or people with learning disability.

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

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| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- We agree that Learning Disability and Autism should be viewed as disabilities.
- Legal capacity with the absolute right to provision of effective communication support represents a significant and positive shift in the recognition of human rights of autistic people and people with learning disability.
- National strategies from Scottish Government (Keys to Life, National Autism Strategy) clearly identify a human rights approach to support and care..
- There has been a lack of clarity for children and adults with autism and / or learning disability of role of mental health services. The approach of services varies across Scotland and clarity on what is expected of services would lead to better outcomes.

3. Could these ideas be made better?

| | |
|-------------------------------------|-----|
| <input checked="" type="checkbox"/> | Yes |
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| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |

No

I don't know

4. How could these ideas be made better?

- We agree that people with autism and / or learning disability should be viewed as having legal capacity and that there should be legal safeguards in place to protect rights.
- Guaranteed support in decision making in the context of mental health will be required to make rights a reality. Law should refer clearly and unambiguously to the fundamental and almost universal need for inclusive communication support for autistic people and people with learning disability.
- Definition of that support will be crucial and will require input from SLT to determine what communication is required by each individual.
- Assessment of capacity (i.e. the ability to understand, express and remember choices) is equal to an assessment of communication capacity in the first two respects. SLTs are best placed to carry out that assessment effectively.
- Speech & Language Therapists as qualified clinicians are uniquely trained among health care professionals to provide such support.
- In order for SLT services to meet demand they require to be connected with mental health care pathways and the profession would welcome clear legal duties to set the context for future service delivery.

3. Support for decision making

We suggest that Scotland should make change to comply in full with a key right in the Convention on the Rights of Persons with Disabilities, the right to equal recognition before the law.

To make it possible for autistic people and people with learning disability to have and use their legal capacity, Scotland would have to give strong support for decision making. We make a range of suggestions on how this support should be set up.

We also discuss how we think decisions should be made on psychological interventions, psychotropic medication, and at times of crisis.

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

| |
|--------------------------|
| X |
| <input type="checkbox"/> |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

I like the ideas

I have mixed views about the ideas

I do not like the ideas

I do not understand the ideas

2. Why do you think that?

- Proposal to use a statement of ‘rights, will and preferences’ is appropriate and unambiguous.
- Agree that the form of statement only needs to be made in a way that is permanent; this allows for different communication systems to be used. The use of alternative formats (e.g. pictures) should align with the individual’s comprehension strengths – that is the type of communication the person finds easiest to understand.
- Human rights assessments will be a necessary step before deviating from a statement.
- Agree that supporting people with mental health conditions where evidence base for care and treatment may be limited would be supported with informed consent and a rights based approach.
- Improved clinical guidance on use of medicines is clearly needed as is improved monitoring of the prescribing of psychotropic medications.

3. Could these ideas be made better?

| | |
|---|--------------|
| X | Yes |
| | No |
| | I don’t know |

4. How could these ideas be made better?

- The attitude, knowledge, skills and experience (competencies) of ‘independent advocate’ would need to be determined. Communicating with and assessing the preferences of people with communication difficulties is a highly complex task that should be overseen by a qualified clinician.
- We would recommend specific training in use of inclusive communication approaches for independent advocates. RCSLT can advise on competencies and learning from relevant intermediary services elsewhere in the UK.
- Human rights assessment should be viewed ‘in the round’ and preferably not based on any one professional’s opinion as differently trained professionals may focus on certain aspects of a person’s life.
- In cases where people have significant communication support needs and are having difficulty considering decisions it should be clearly understood when ‘best evidence’ of a person’s preferences is being used.
- The Scottish Government and others have published principles of inclusive communication. The recent Social Security Scotland Act placed a duty on the new agency to implement inclusive communication approaches in primary legislation. Given the almost universal need for inclusive communication approaches in this population we propose similar regulation for a new Mental Health Act.
- Welcome Review’s proposal that access to support and resources to fully support people such as SLT should be monitored for quality and effectiveness.
- Review needs to be aware that SLT services support a wide range of children and adults with communication and swallowing support needs.

Funding for services, and the numbers of SLT in the NHS, have been static for a number of years while at the same time demand for SLT and the range and complexity of needs have increased.

- Health Boards and Health & Social Care Partnerships will need to be provided with resources and funding to meet new duties.

4. Support, care and treatment

We suggest that autistic people and people with learning disability should be given rights in law to have access to the support, care and treatment that they need.

We also makes suggestions on how support, care and treatment could be provided for women, children and offenders, in ways that respect human rights.

We discuss some duties that would need to be placed on public authorities to make these rights real.

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

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|-------------------------------------|------------------------------------|
| <input type="checkbox"/> | I like the ideas |
| <input checked="" type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- It may be considered discriminatory to only make these provisions for people with learning disability and autistic people. We agree that legal rights will strengthen provision for currently underserved populations however human rights provisions may be weakened if linked to a diagnosis.
- General and specialist services are normally provided to people on the basis of need and not diagnosis. We fully support making provision for the needs of autistic people and people with learning disability through adaptation.
- Agree that a proposed National Autism Service should have a multi-disciplinary group of professionals involved.
- Agree that support should clearly be extended to offenders, evidence base identifies a significant presence of communication support needs among offending population.

3. Could these ideas be made better?

- | | |
|-------------------------------------|-----|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |

I don't know

4. How could these ideas be made better?

- Agree need look at General Medical Services contract, this should be widened to understanding the role the multi-disciplinary team in primary care should play in support.
- There is a significant focus on screening, assessment and diagnosis but this should be connected with support to help people live positive lives and prevention of crises with support from multi disciplinary teams and services.
- Rights based approach could be improved by more fully exploring 'intersectionality' – where a person has experience of more than one protected characteristic – to include ethnicity, race and sexuality etc.

5. Where support, care and treatment happens

We suggest that there should be a shift towards voluntary support and care that emphasises social support and care. We suggest a shift away from compulsory treatment in hospitals that emphasise medical treatment.

We suggest places where support, care and treatment should happen. This includes a new type of service which we call secure support centres.

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

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|-------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- Agree that placement in hospital and out of area provision reflects a lack of good community based provision and that this limits individual choice.
- These options do not always deliver best outcomes for individuals or represent value for money.
- Use of care homes is not an appropriate environment and choices should reflect personal decisions.
- Appropriate housing and community support, including non-statutory services, is a better model.
- Agree that specialist secure support centres are a better option to hospital care, and should be available for those who are not presenting with a mental illness.
- Identifying autism and learning disability in the mental health population is an important step to take. Many older adults have not been identified and are often misdiagnosed and receive inappropriate support as a result.

Identification in older people can be difficult and time consuming but practice in emergency services can and should be improved.

3. Could these ideas be made better?

| | |
|-------------------------------------|--------------|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |
| <input type="checkbox"/> | I don't know |

4. How could these ideas be made better?

- When preparing a statement of rights a clear understanding of what an individual defines as their 'safe place' should be obtained. Many autistic people or people with learning disability will have their own idea or preferences for what they regard as 'safe'.
- New forms of secure support centres should be monitored and regulated and responsibilities of Care Inspectorate, new National Autism Service and others should be clarified.
- Planning duties around discharge will be very important to prevent delays in transitions back to community support.
- Without changes being made to significantly improve links to community services there is a risk that secure support centres become secure hospitals with a different name.
- The Review needs to commit to developing an evidence base for the base form of secure support before deciding what model or structure to support.

6. How professionals make decisions

We suggest that Scotland should make changes to move closer to compliance with the right to liberty and security. This is another key right in the Convention on the Rights of Persons with Disabilities.

We suggest that Scotland is not yet ready to end all detention on the basis of disability, or all compulsory treatment, in a safe way.

We suggest that human rights assessments should be the basis for all professional decision making for autistic people and people with learning disability.

We suggest new roles for a broad range of professionals.

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

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| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- Support an approach built on a statement of rights, will and preferences and use of human rights assessments by professionals.
- Agree there should be a presumption in favour of a person's will and preferences.
- Agree there should also be a proportionate response when a professional has to do something against a stated will and preference.
- Support the development of the Mental Health Officer role to carry out human rights based assessments. We recommend human rights based assessment should be communication inclusive and include assessment of how communication inclusive the person's service experience is.
- Support the recommendation that change is needed over time and that international frameworks provide a clear road map for the type of change required.
- Agree there is urgent clarification needed on what is treatment and what is a restriction of liberty.

3. Could these ideas be made better?

| | |
|-------------------------------------|--------------|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |
| <input type="checkbox"/> | I don't know |

4. How could these ideas be made better?

- Applying a human rights based approach should form a core component of training and Continuing Professional Development for health care professionals.
- Preparation and training for Tribunal representation for health care professionals should be improved, we recommend that support be made available from the Tribunal for this.
- When considering the duties of the police the Review could also look at the current provision of 'Appropriate Adults' role and discussions relating to developing a statutory Appropriate Adult Service. RCSLT are advising on communication related competencies
- The proposals for more appropriate environments and community connections will require significant input from Allied Health Professionals. A clearer vision for the roles of AHPs would ensure environments provide appropriate care, treatment and support.

7. How decisions are monitored

We think that Scotland needs mental health law and services based on human rights. We think that autistic people and people with learning disability should be routinely involved in developing, implementing and monitoring the law and services.

We suggest that the Mental Welfare Commission for Scotland and the Mental Health Tribunal for Scotland should be more authority to protect the rights of autistic people and people with learning disability.

We make a range of suggestions on how human rights should be monitored.

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

| | |
|---|------------------------------------|
| x | I like the ideas |
| | I have mixed views about the ideas |
| | I do not like the ideas |
| | I do not understand the ideas |

2. Why do you think that?

- In light of scandals such as Winterbourne a rigorous inspection system of mental health services is required.
- People with learning disability and autistic people with lived experience should be involved in the developing the services and laws that will affect them.
- Support the recommendations to make Tribunals more accessible. Accessibility should be extended to cover non-verbal communication.
- Agree with the proposal that a 'shift in culture' is needed to fully prevent limits to liberty based on disability.
- Agree that each form of support, care or treatment should be considered separately. This should help communication support needs to be clearly

assessed and monitored.

3. Could these ideas be made better?

| | |
|-------------------------------------|--------------|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |
| <input type="checkbox"/> | I don't know |

4. How could these ideas be made better?

- On the matter of second professional opinion, we should aim for front line services to be enabled to make the right decisions. Access for professionals to specialist support should also be available to improve decision making in complex cases.
- Consider if the Care Inspectorate and Healthcare Improvement Scotland should also have a role in monitoring and supporting services.
- The role proposed for the Equality and Human Rights Commission would appear to be proportionate and the Commission may wish to consider recommending a duty to report to the Scottish Ministers and the Scottish Parliament on an annual basis to support scrutiny.

8. Offenders

We suggest changes to make the criminal justice system fairer for autistic people and people with learning disability.

We suggest that Scotland uses 'intermediaries' to support suspects and defendants who have communication impairment.

We suggest a change to how disability is understood in criminal law. This change could make it possible for person to be held responsible for an offence, but also to have adapted consequences that take account of the person's disability.

We suggest that punishment, treatment and support to stop offending should be clearly separated out in law for autistic offenders and offenders with learning disability.

We suggest that punishment should not be longer for these offenders than for any other offenders.

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

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|-------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |

| |
|--------------------------|
| <input type="checkbox"/> |
| <input type="checkbox"/> |

I do not like the ideas

I do not understand the ideas

2. Why do you think that?

- Agree fully with the Commission's approach to promote equal access to justice and for this to cover the full cycle from police interview through to pre-trial, trial, sentencing and appeal.
- Courts in Scotland have developed adjustments and we think could benefit from a consistent standard set in law.
- There is an important role for Speech and Language Therapy to support the assessment and provision of adjustments for those going to trial.
- We strongly support the proposal for 'registered intermediaries' involving speech and language therapists. Very few SLTs currently work in the justice sector in Scotland but the profession recognises that there are substantial needs and SLTs make up the intermediary workforce roles in N Ireland and England.
- We agree with the Commission's view that some autistic people and people with learning disability have not been supported to understand social rules in a way which they can understand. These factors need to be taken into consideration of mitigating factors.
- We agree that the proper management of autistic people and people with learning disability in prison settings is likely to require specially adapted facilities, particularly if they are to receive therapeutic support.

3. Could these ideas be made better?

| |
|--------------------------|
| x |
| <input type="checkbox"/> |
| <input type="checkbox"/> |

Yes

No

I don't know

4. How could these ideas be made better?

- In addition to considering the provision of specialist facilities the quality and ability of staffing will be equally crucial to providing the best services. These staff teams will be multi-disciplinary and will require a high level of leadership and Continuing Professional Development (CPD) to deliver the support and care required.
- Intermediaries should be made available at all points in the system and for witnesses and victims.
- Gaps in community provision and delayed discharge can lead to unfair disadvantage for people with learning disability and autistic people and for them to be detained for longer periods. Sufficient and appropriate community provision will need to be planned for.

9. Where support, care and treatment happens for offenders

We suggest that rehabilitation should usually happen in the community, for offences that would usually lead to community rehabilitation for anyone else.

We suggest that offenders should usually be given support, care or treatment in the community or in rehabilitation centres, not in hospitals.

We suggest that prison should only be used for autistic offenders or offenders with learning disability when it is specially designed or adapted to meet the person's needs.

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

| | |
|-------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- We agree that autistic people and people with learning disability should expect to be treated equally in the criminal justice system.
- We agree that rehabilitation should be 'socially-led' with support from health and other services.
- Services should be developed to be appropriate to the offence and also to provide appropriate care and treatment.

3. Could these ideas be made better?

| | |
|-------------------------------------|--------------|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |
| <input type="checkbox"/> | I don't know |

4. How could these ideas be made better?

- Consideration should be given to the management of transitions and how best Health & Social Care Partnerships can guarantee continuation of care and support when an individual transfers for example, from a rehabilitation centre to community living.
- Community services as well as prisons will need to adapt and require a multi disciplinary approach from health and social care professionals. Sufficient resources and skilled staffing will be required to achieve the best outcomes.

10. What this means for the law

We suggest that autism and learning disability should no longer be defined as 'mental disorders' in Scotland's Mental Health Act.

We suggest that Scotland develops a new law to give 'positive rights' for support, care and treatment to autistic people and people with learning disability.

We give a summary of the changes that we are suggesting for criminal law.

We suggest how Scotland might prepare to end detention on the basis of disability, and to end compulsory treatment, at some time in the future.

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

| | |
|-------------------------------------|------------------------------------|
| <input checked="" type="checkbox"/> | I like the ideas |
| <input type="checkbox"/> | I have mixed views about the ideas |
| <input type="checkbox"/> | I do not like the ideas |
| <input type="checkbox"/> | I do not understand the ideas |

2. Why do you think that?

- We agree that a new legal framework should be developed before removing autism and learning disability from the provisions of the Mental Health Act.
- Any new framework should reflect the rights promoted in the UNCRPD and ECHR.

3. Could these ideas be made better?

| | |
|-------------------------------------|--------------|
| <input checked="" type="checkbox"/> | Yes |
| <input type="checkbox"/> | No |
| <input type="checkbox"/> | I don't know |

4. How could these ideas be made better?

- In defining the scope of a new law we believe a broader definition may be needed to cover the full range of people with communication disabilities and to not be discriminatory between such disabilities.

Section 2.4 About you

We would like to know a bit about you. You do not have to answer these questions but it is very helpful for us if you do.

We keep all your information private. Our privacy statement is available on our website. If you would like us to send a copy to you, please contact us.

1. What is your name? This helps us to know if you have answered more than one survey.

Robert MacBean

2. What is email address? This helps us to know if you have answered more than one survey.

robert.macbean@rcslt.org

3. Are you taking part in this survey as...?

- An individual
- A professional
- A group

4. Do any of these apply to you? (please tick all that apply)

- I am a person with learning disability
- I am an autistic person
- I am an unpaid carer for someone with learning disability
- I am a carer of an autistic person
- None of the above

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

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

The Royal College of Speech & Language Therapists

7. Do you live in Scotland?

- Yes
- No

9. Do you want us to publish your response? This means that after the survey closes your response will be published on a Citizen Space web page until June 2020

- Yes please publish my response anonymously
- No

If you would like to make any further comments, please do so here:

A large, empty rectangular box with a thin black border, intended for the user to provide further comments or feedback.

Equality monitoring form

This form asks some details about you. You do not have to fill it in, but if you do it will help us make sure we are treating people equally.

Anything you tell us on this form will be anonymous. We will use it only for our statistics. We won't link it to your answers.

Where you live

We are asking where you live because our review is about Scottish Law and we want to make sure all of Scotland is covered.

Where in Scotland do you live? _____

Age

We ask about your age because we want to hear from lots of different age groups.

How old are you? _____

Prefer not to say

Gender identity

We ask about gender identity because research shows that people who are trans experience high rates of poor mental health. We want to make sure we hear from all genders.

| | |
|---|--|
| <p>Are you:</p> <p><input type="checkbox"/> Male (including trans man)</p> <p><input type="checkbox"/> Female (including trans woman)</p> <p><input type="checkbox"/> Other gender identity - please tell us what:</p> <p>_____</p> <p><input type="checkbox"/> Prefer not to say</p> | <p>Have you ever identified as transgender?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Prefer not to say</p> |
|---|--|

Sexual identity

We ask about sexuality because research that shows that people who are lesbian, gay or bisexual experience high rates of poor mental health. We want to make sure we hear from all sexual identities.

Which of these best describes how you think of your sexuality?

- Heterosexual or straight
- Gay or lesbian
- Bisexual
- Other sexuality - please tell us what: _____
- Prefer not to say

Ethnic origin

We ask about ethnic origin because there is research that shows that some ethnic groups might have different experiences of mental health services from others.

- Prefer not to answer

White

- Scottish
- Other British (English, Welsh, Northern Irish)
- Irish
- Gypsy/Traveller
- Polish
- Any other white ethnic group, please describe:

Asian, Asian Scottish, Asian British

- Pakistani, Pakistani Scottish, Pakistani British
- Indian, Indian Scottish, Indian British
- Bangladeshi, Bangladeshi Scottish, Bangladeshi British
- Chinese, Chinese Scottish, Chinese British
- Any other Asian, please describe:

African

- African, African Scottish, African British
- Any other African, please describe:

Caribbean or Black

- Caribbean, Caribbean Scottish, Caribbean British
- Black, Black Scottish, Black British
- Any other Caribbean or Black, please describe:

Other ethnic group

- Arab, Arab Scottish, Arab British
- Any other ethnic group, please describe:

Any mixed or multiple ethnic groups

- Please describe:

Thank you for completing this survey

If you need help to with this survey, you can call us at

0131 313 8744

You can send the survey back to us by email

irmha.scot@nhs.net

You can send it by post to

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