

Submitted to **1. Summary survey**

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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?:

- 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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I have mixed feelings about the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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

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

I like the ideas

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.

2 Could these ideas be made better?

Yes

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.

About you

1 What is your name?

Name:

Robert MacBean

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:

The Royal College of Speech and Language Therapists

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: