Review of learning disability and autism in Scottish mental health law – a scoping consultation
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1. Introduction

1.1 During the recent Parliamentary debate on the Mental Health Bill (now the Mental Health (Scotland) Act 2015), the Scottish Government made a commitment to review the place of learning disability and autism within the Mental Health (Care and Treatment) (Scotland) Act 2003 (referred to in this document as the 2003 Act). The Scottish Government is clear that the review must be genuinely participative and must not start with a pre-determined outcome or process. It requires a flexible approach that can adjust to the views of those who are involved. At present the review has no specific remit except that it will consider views and other evidence for removing learning disability and autism from the definition of ‘mental disorder’ under the 2003 Act, and all options are possible.

1.2 As the first stage in the review, the Government has asked the Mental Welfare Commission for Scotland (MWC) and the Scottish Commission for Learning Disability (SCLD) to undertake a small-scale scoping study to identify which issues the review should consider, who should be involved, and how the review should be conducted. This preliminary consultation is being carried out as part of this first stage of the review.

1.3 The purpose of this consultation is not to seek views about whether a review is necessary. A review will take place, and Sections 2 and 3 of this paper set out the reasons that the review is being undertaken. This preliminary consultation invites comments (see Sections 4 and 6) about:

- Which issues the review should consider (the Government has specifically said that the review will consider, at least, the following issues: (i) the role of psychologists under the 2003 Act, and (ii) the use of psychotropic medication)
- Who should be involved in the review
- How the review should be conducted

1.4 It is important that the wider review focuses on the things that matter most to the people with direct experience of the issues involved – as service users, family members, carers and professionals. It is also important that the review is carried out in a way that allows people from a wide range of groups to participate and contribute their views.

1.5 This initial scoping exercise will involve consulting key groups to hear their views on the priorities for the full review, and how they think the review should be carried out. This will ensure that the full review considers the things that are important to people, and is a meaningful and successful process for all involved.

1.6 The scoping work is being overseen by MWC and SCLD, and will include:

- A preliminary consultation based on this paper
- Interviews with a small number of people to explore issues in more depth
• Two working meetings involving representatives from relevant sectors and organisations to allow discussion of the findings from the preliminary consultation about the focus and methods for the main review
• A report to the Scottish Government about the focus and methods of the full review.

1.7  At this stage, consultees are being asked to take the time to consider the information and questions presented in this paper and to give their views using the online questionnaire provided (see Section 7 for details). All the responses will be carefully considered, along with the information gathered in the interviews, and this information will be used to plan the working group meetings which will be held in August / September. A report, with recommendations regarding the scope of the full review and process for conducting it, will be submitted to the Scottish Government in the autumn.
2. Why is a review needed?

2.1 The 2003 Act provides the legal framework in Scotland for dealing with people with mental disorders who require compulsory detention and treatment. The Act applies only to people who have a mental disorder, and ‘mental disorder’ is defined as including mental illness, learning disability and personality disorder. The Act sets out the conditions and legal protections under which detention in hospital and/or compulsory treatment may be carried out, as well as a set of governing principles (the ‘Millan principles’). The Act also imposes a range of duties on public bodies to provide support including through independent advocacy and local authority services.

2.2 Autistic spectrum disorders (ASD) are also covered by the 2003 Act, although ASD is not, in itself, one of the three categories of mental disorder named in the Act. This has led to some confusion among professional care providers about how the 2003 Act should be used for people with ASD.

2.3 The 2003 Act resulted from a report of the Millan Committee in 2001. At the time, the 2003 Act was seen to be a significant advance on the Mental Health Act of 1984, which it replaced. However, during the consultations carried out by the Millan Committee there was considerable debate – and no clear consensus – about whether learning disability and autism should be included in the new mental health law. The Millan Committee recommended inclusion in the Act, but also recommended that this arrangement should be reviewed at an early opportunity.

2.4 Since the Act came into force, concerns about the inclusion of people with learning disabilities and ASD have continued to be voiced and there have been repeated calls from those in the learning disability and autism communities for the law to be reviewed and amended as it relates to people with these conditions.

Recommendation of the Millan report

2.5 In its consultations, the Millan Committee considered evidence and input from a wide range of perspectives. During this process, strong views emerged for and against inclusion of those with learning disability and autism in the new mental health law.

2.6 On the one hand, there was a view that learning disability and autism should not be included for the following reasons:

- The Mental Health Act is based on the idea that people who may require treatment, but who do not accept the need for it, may be detained in hospital, under the care of a psychiatrist, to receive such treatment. However, learning disability and ASD are lifelong conditions, which cannot be cured or treated by medication. If a person with a

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learning disability or ASD also has a mental illness, then that person may be detained, if necessary, under mental health law – without any reference to their learning disability or ASD.

- People with learning disabilities or ASD are more likely to receive support from a psychologist, rather than a psychiatrist, to address any problems related to these conditions such as problems with aggression, or distressed behaviour (sometimes referred to as ‘challenging behaviour’). However, the Mental Health Act contains no specific safeguards in relation to such interventions.

- Stressed and distressed behaviour may reflect inappropriate or inadequate services. In this case, the correct response is to provide the appropriate services, rather than place the individual under greater constraints. Concerns were voiced that the Act can result in people being detained for lengthy periods because the right services are not available.

- The continued inclusion of learning disability and autism in mental health legislation contributes to the marginalisation of people with these conditions.

2.7 However, the counter-arguments in favour of including learning disability and autism in the Mental Health Act were that:

- It is not uncommon for people with learning disability and autism to also have some form of mental illness. Diagnosis in such cases can be difficult and may require close observation in a controlled setting over an extended period of time.

- Even if a mental illness is not present, it may be appropriate to give medication to manage stressed and distressed behaviour, or it may be necessary to provide restrictive care. These interventions require safeguards beyond those available in common law or under incapacity law.

- If learning disability and autism were removed from the Act, it may mean that people with these conditions whose behaviour is inappropriate or illegal might otherwise end up in prison. This was seen to be inhumane, as well as unhelpful, since it would make it harder to address the causes of the offending behaviour.

2.8 The Millan report ultimately recommended that both learning disability and autism should continue to be covered by mental health law in Scotland. However, the report acknowledged that there were significant difficulties in this, and that people with these conditions may not be well served by a legislative framework which was primarily created for people with mental illness. Thus, the Millan committee also recommended that this arrangement should be reviewed at an early date, and that consideration should be given to whether separate legislation should be developed to address the specific needs of this group.
**Millan report, recommendation 4.6:** There should be an expert review at an early date of the position of learning disability within mental health law. This review should consider:

- The implications of the Scottish Executive review of learning disability services for legislation affecting people with learning disability, including mental health law
- Experiences from jurisdictions with different arrangements in respect of learning disability and compulsory care
- Whether it is feasible and desirable to make separate provision for the compulsory care of people with learning disabilities, outwith the Mental Health Act
- The experiences of people with learning disabilities who have been detained, including their treatment and outcomes
- What measures might be taken to ensure that arrangements for people with learning disabilities who offend meet the needs of the offenders and society.

**Ongoing concerns about the use of the 2003 Act for people with learning disabilities and ASD**

2.9 Since the introduction of the 2003 Act, there has been continuing debate and concern about the inclusion of those with learning disabilities and ASD. In particular, there have been ongoing objections to the principle of including learning disability and autism in the 2003 Act as ‘mental disorders’, given that these are lifelong conditions which cannot be cured or treated with medication (unlike mental illness).

2.10 There have also been concerns about the way in which the law is being applied to people with learning disability / autism, given: (i) the increasing number of people with learning disabilities subject to compulsory measures under the Act; and (ii) the evidence that individuals with a learning disability are, on average, detained for much longer periods of time than other individuals (i.e. those with mental illness).

**The increasing number of people subject to compulsory measures**

2.11 Up until 2012, MWC undertook a census every two years of all people with learning disability who were being given compulsory treatment.\(^2\) The latest census report (published in 2013) indicated that between 2006 and 2012, there was a 39% increase in

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\(^2\) This census is no longer carried out, as MWC now undertakes more targeted investigation of specific issues affecting people with learning disability who are subject to the 2003 Act.
the number of people with learning disabilities subject to compulsory measures. The numbers of people involved have also steadily risen – from 252 in 2006, to 351 in 2012. In comparison, in the same period, there was just a 7% increase in the use of compulsory measures for people without learning disabilities.

Duration of detention
2.12 Research conducted for the Millan review in 1999 found that, on average, the duration of detention for people with learning disabilities was significantly longer than that for people with a mental illness.

2.13 This situation appears to have changed little in the past 15 years.

2.14 The MWC’s 2012 census (mentioned above) found that the median length of compulsion for people with learning disabilities was four years, compared with 1.8 years for those without learning disabilities. More recent research undertaken by MWC in 2016 compared the length of detention for people with and without a learning disability, and found that the average length of detention for a person with a learning disability was (still) nearly twice as long as that for a person without a learning disability.

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5 Unpublished research carried out by Mental Welfare Commission.
3. Changes since the Millan report

3.1 Since the Millan report was published, there have been significant developments in law, human rights and services for people with learning disability and autism – both in Scotland and internationally – which are relevant to the proposed review. Some of these developments are outlined briefly below. Consultees may wish to consider these – and any other relevant developments – in giving their views about what should be included in the scope of the review.

There is an increasing focus on human rights and the rights of disabled people

3.2 In the decade since the 2003 Act was introduced, there has been an increasing focus in all areas of public life on the importance of protecting and promoting human rights, and on recognising the rights of people with disabilities. The European Convention on Human Rights and the United Nations Convention on the Rights of Persons with Disabilities have provided the impetus for this increased focus.

3.3 There has been a consistent effort in Scotland to incorporate a human rights-based focus into new legislation and policy, and there has been an increasing interest in whether and how legislation can promote positive social and economic rights, as well as protect individual freedoms. Some recent initiatives are described below.

Scotland’s National Action Plan for human rights

3.4 *Scotland’s National Action Plan for Human Rights* was launched by the Scottish Human Rights Commission in December 2013 making it the first such plan in any part of the UK.\(^6\) The Action Plan sets out a ‘roadmap’ towards a Scotland where everyone can live with human dignity, and where international human rights are realised in people's lives.

3.5 The Action Plan includes specific aims in relation to health and social care. Research carried out to inform the development of the Action Plan found many examples where human rights were taken into consideration by health and social care providers. However, there were also many examples where health and social care services were not currently designed to enable the workforce to practice a human rights-based approach as a matter of course. Inconsistent practice was found, and it was noted that there have been well documented cases where practice has fallen far below human rights standards.

3.6 The Action Plan sets out eight actions which aim to enhance respect for, protect and fulfil human rights to achieve high quality health and social care. Two of these actions – particularly relevant to people with learning disabilities and ASD – are: (i) to take action to realise the right to independent living for all, including through self-directed support; and (ii) to improve understanding and practices to uphold autonomy, including through

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Scotland’s learning disabilities strategy and reviews of law and practice on mental health, legal capacity and guardianships.

Learning disability and autism strategies

3.7 The Scottish Government’s Strategy for Autism (2011) and its learning disability strategy, *The Keys to Life* (2013), are both premised on a commitment to human rights. They have four strategic outcomes in common which relate to people with autism and people with learning disabilities:

- **A healthy life**: people enjoy the highest attainable standard of living, health and family life
- **Choice and control**: People are treated with dignity and respect, and protected from neglect, exploitation and abuse
- **Independence**: People are able to live independently in the community with equal access to all aspects of society
- **Active citizenship**: People are able to participate in all aspects of community and society

3.8 These outcomes relate to the United Nations Convention on the Rights of People with Disabilities. Ongoing delivery plans and priorities for both strategies are being designed to help achieve these outcomes.

Other legislation and policy initiatives

3.9 The United Nations Convention on the Rights of People with Disabilities was ratified by the UK in 2009. This built on the UN Convention on Human Rights, making it clear that people with disabilities should benefit from human rights in the same way as all other citizens. There is considerable debate about what this means for mental health law. The UN Committee which supports the Convention has argued that it requires an end to forced treatment, the replacement of ‘substituted decision making’ by ‘supported decision making’, and that any change in legal status which depends on a definition of a mental disability is discriminatory and should end. Others have argued that this is unrealistic and, in itself, discriminatory in not recognising the needs of people who are unable to protect their own interests.

3.10 Between September 2015 and January 2016, the Scottish Government undertook a public consultation on its Draft Delivery Plan 2016–2020 for implementing the UN Convention on the Rights of Persons with Disabilities in Scotland. Commitment 31 of this draft plan states that ‘the Scottish Government will review the inclusion of people with learning disabilities or autistic spectrum disorders under the Mental Health (Care and Treatment) 

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7 *The Keys to Life*. Available at: http://keystolife.info/

There is also a commitment to ‘consider circumstances in which supported decision making can be promoted’.

3.11 The UK Equality Act 2010 brought together existing equality and discrimination legislation. It includes disability as one of the ‘protected characteristics’ covered by the Act. It also introduced a public sector equality duty, meaning that public bodies must have ‘due regard’ to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. In Scotland, Ministers also introduced regulations placing specific duties on public authorities to enable the better performance of the public sector equality duty.

3.12 The Scottish Government’s Mental Health Strategy 2012–2015 included a commitment to work with MWC and Scottish Human Rights Commission to increase the focus on ‘rights’ in mental health care in Scotland. This led to a report, which called for the next mental health strategy to be explicitly based on a human rights approach. Submissions to the Government on the next mental health strategy by the Rights for Life campaign and the MWC have called for new, rights-based mental health legislation.

There have been major changes in learning disability services in Scotland

3.13 In addition to the increasing focus in Scottish Government policy and legislation on human rights and the rights of disabled people, there have also been substantial changes in services for people with learning disability and autism over the past 15 years. Specifically, the majority of people are now supported in the community, rather than in hospitals or other institutions.

3.14 This change was initiated by a major review of learning disability services – The Same as You? – carried out in 2000. The Same as You? led to the final phase of learning disability hospital closures by stating that, ‘People’s homes should not be in hospitals’, and recommending that health boards should ‘reduce their assessment and treatment places specifically for people with learning disabilities to four for every 100,000 population’ – or around 300 nationally (Recommendation 13).

3.15 At the time of its publication in 2000, The same as you? recorded that around 2,450 adults with learning disabilities were living in a hospital setting. By contrast, data collected in 2014 showed that just a small number of adults with learning disabilities (235) lived in NHS facilities / hospitals and a further 15 lived in independent hospitals.
However, the majority of adults (60.3%) lived in mainstream accommodation, defined as ‘their own home or the family home’.

3.16 Scotland’s current learning disability strategy, *The Keys to Life*, acknowledges that the overwhelming majority of adults with learning disabilities now live in a non-institutional setting. It also recognises that the focus should be on the provision of services and supports which facilitate independent living and improved quality of life, so that people with learning disabilities can live within the community as equal members of society.

**Longer hospital stays**

3.17 While the changes described above have been very positive, it is clear that people with learning disability and autism continue to have much longer stays in hospital when compared to other mental health patients – whether or not they have been detained compulsorily in hospital (as discussed in paragraphs 2.12–2.14 above).

3.18 The Scottish Government’s *Mental Health and Learning Disability Inpatient Bed Census, 2014* found that the average stay in hospital for a patient with learning disability or autism was 33 months (2 years and 9 months), compared to 5 months for other adult mental health patients.\(^\text{13}\)

3.19 Data collected one year later by MWC – between August and October 2015 – found that out of a total 180 patients in learning disability hospital units in Scotland (excluding forensic units), one-third (32%, n=58) were classed as ‘delayed discharges’. The reasons for the delays included lack of identified funding for community placements (41%), lack of an identified or appropriate support provider (62%), lack of identified housing or accommodation (74%), and other reasons (24%). A combination of reasons was recorded in 60% of cases.\(^\text{14}\)

**Mental health and capacity legislation in Scotland has become increasingly complex**

3.20 In addition to the 2003 Act, there are two other laws in Scotland that are often used to ensure that people with learning disability or autism get appropriate treatment, or that their rights are protected and respected. These are the *Adults with Incapacity (Scotland) Act 2000* (the 2000 Act) and the *Adult Support and Protection (Scotland) Act 2007* (the 2007 Act).

\(^{13}\) Scottish Government (2015) *Mental health and learning disability bed census, 2014*. Available at: [http://www.gov.scot/Resource/0048/00480638.pdf](http://www.gov.scot/Resource/0048/00480638.pdf). This survey gathers information on a census date (in this case, midnight at the end of 29th October 2014) about every patient occupying a psychiatric, addiction or learning disability inpatient bed in an NHS Scotland facility, and about every mental health, addiction or learning disability patient whose care is funded by NHS Scotland, but who is being treated in a facility outside NHS Scotland.

Adults with Incapacity (Scotland) Act 2000

3.21 The 2000 Act was one of the earliest pieces of legislation to be passed by the Scottish Parliament. This law provides a framework for safeguarding the welfare and managing the finances of adults (people 16 and over) who lack capacity due to a mental illness, learning disability or other related condition, or due to an inability to communicate. It allows arrangements to be put in place to give others the authority to act or make decisions for someone who lacks capacity to do so for him/herself. Importantly, this can include decisions about placing people in care settings, or about medical treatment, and there is a complex interplay with the 2003 Act.

3.22 People with learning disability and autism are frequently subject to Guardianship Orders under the 2000 Act, even if they are not subject to the 2003 Act. Indeed, in 2014/15, for the first time since monitoring began, the number of guardianship applications granted for adults with learning disability (n=1,104) was greater than the number of applications grants for people with dementia (n=1,056). Moreover, just over a third (34%, n=833) of all guardianships granted in 2014/15 for people aged 16-45 were on behalf of people with a learning disability.15

3.23 The UK Supreme Court has issued an important decision (the ‘Cheshire West’ ruling16) which suggests that many people with learning disabilities or autism who are not able to agree to their care arrangements have been deprived of their liberty and require additional legal safeguards to comply with the European Convention on Human Rights. Following this, the Scottish Law Commission (SLC) recommended changes to the 2000 Act, including new procedures to allow restrictions on liberty to be authorised by doctors (in hospital) or courts and welfare guardians (in the community), and to give new rights to challenge deprivation of liberty imposed without proper legal authority.17

3.24 The Scottish Government recently undertook a public consultation on the SLC report. The Government’s consultation paper sought views on specific matters raised in the SLC report, with particular reference to the SLC’s draft Bill18 and how that would work alongside the existing legislation. The consultation also took the opportunity to seek general views on wider aspects of the 2000 Act that may benefit from review. The findings from this consultation will inform decisions regarding any wider review of the 2000 Act. The responses are currently being analysed and will be published in the summer.19

16 See http://www.bailii.org/uk/cases/UKSC/2014/19.html
18 The draft Bill comprised a proposed amendment to the 2000 Act and 2003 Act.
19 The Scottish Government consultation closed on 31 March, but the consultation document may still be viewed at: http://www.gov.scot/Publications/2015/12/8931.
Adult Support and Protection (Scotland) Act 2007

3.25 The 2007 Act provides protection to adults at risk of being harmed. It places a duty upon local councils and other public bodies to work together to support and protect adults who are unable to protect themselves, their property and their rights. An ‘adult at risk’ is defined in the law as a person aged 16 years or over who:

- May be unable to safeguard his/her well-being, rights, interests or property
- May be harmed by other people
- Because of a disability, illness or mental disorder is more at risk of being harmed than other people.

3.26 Having a particular condition such as a learning disability or autism does not automatically mean that an adult is at risk. The law only applies to adults who meet all three parts of the definition, and the law can be used when the individual is at risk of neglect or physical, psychological, financial or sexual harm. Among other things, the law allows local councils to make enquiries and carry out investigations to see if action is needed to stop, or prevent, harm from happening. The Act also allows for the use of a range of protection orders including ‘assessment orders’, ‘removal orders’ and ‘banning orders’.

Other countries have dealt with this issue differently

3.27 The inclusion of learning disability and autism within mental health law is common throughout the world, but some countries have approached compulsory care for these groups in different ways. Examples are given below from Northern Ireland and New Zealand, and the situation in England and Wales is also discussed.

Northern Ireland

3.28 Following the Bamford Review of Mental Health and Learning Disability, Northern Ireland has become the first country in the world to combine mental health and mental capacity law into a single piece of legislation.\(^{20}\)

3.29 The new Mental Capacity Act (Northern Ireland) 2016 (which received Royal Assent on 10 May 2016) introduces a single, legislative framework governing all situations where a decision needs to be made in relation to the care, treatment (for a physical or mental illness) or personal welfare of persons aged 16 or over, including those subject to the criminal justice system, who lack capacity to make decisions for themselves.

3.30 The legislation is underpinned by four principles (which are explicitly stated in the Act) of: (i) autonomy (respecting the person’s capacity to decide and act, without being subject to restraint by others); (ii) justice (applying the law fairly and equally for all people); (iii)

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\(^{20}\) Further information about the Bamford Review is available here: [https://www.dhsspsni.gov.uk/articles/bamford-review-mental-health-and-learning-disability](https://www.dhsspsni.gov.uk/articles/bamford-review-mental-health-and-learning-disability)
**benefit** (promoting the health, welfare and safety of the person, while having regard to the safety of others); and (iv) **least harm** (acting in a way that minimises the likelihood of harm to the person).

3.31 Importantly, the Act is not ‘diagnosis specific’ – in other words, it can apply to people who lack capacity, whether or not they have any particular disorder or disability. This is a significant development, although the Act has yet to be implemented, and so its effect cannot yet be judged.

**New Zealand**

3.32 In New Zealand, the Mental Health (Compulsory Assessment and Treatment) Act was passed in 1992. This excluded ‘intellectual disability’ (the term used in New Zealand for learning disability) from the scope of the Act, reflecting a view that there was a fundamental difference between learning disability and mental illness. The Millan Committee considered this type of approach for Scotland, but noted concerns that this change in New Zealand had led to some people with an offending history being discharged from hospital, some of whom then went on to commit further offences.

3.33 New Zealand subsequently introduced the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 which was intended to address this situation. This Act created a new, separate framework to enable the provision of appropriate compulsory care and rehabilitation for individuals with an intellectual disability.  

**England and Wales**

3.34 In England and Wales, the Mental Health Act 1983 includes learning disability and autism within its remit. A 2007 amendment to this act specifically states that it applies only to people whose learning disability is associated with abnormally aggressive or seriously irresponsible conduct. See Mental Health Act 2007, part 1, chapter 1, section 2: http://www.legislation.gov.uk/ukpga/2007/12/section/2.

The responses to this consultation expressed mixed views about whether the Mental Health Act 1983 should be changed for people with learning disabilities or autism. The UK Government’s response, published in November 2015, said that it would give ‘further consideration in principle of whether and how the Mental Health Act should apply to people with learning disabilities and / or autism and if this remains appropriate.’

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22 A 2007 amendment to this act specifically states that it applies only to people whose learning disability is associated with abnormally aggressive or seriously irresponsible conduct. See Mental Health Act 2007, part 1, chapter 1, section 2: http://www.legislation.gov.uk/ukpga/2007/12/section/2.


Recently, there have been very serious concerns raised about the treatment of people with learning disability and autism in healthcare settings arising from the Panorama investigation in 2012 of physical and psychological abuse of residents at Winterbourne View, and the death in care of Connor Sparrowhawk in 2013.

Significant efforts are, however, underway to address problems with service quality. For example, work is ongoing to develop quality standards for services for people with learning disabilities and challenging behaviour and guidance is being developed for service commissioners.

Conclusion

These wider changes could have implications for the focus and outcomes of the review.

For example, some people might argue for new legislation which is specifically designed for people with learning disability or autism, and sets out positive rights to support and equal treatment. Others might argue that specific laws for learning disability or autism could add to complexity – some people could potentially be subject to four pieces of legislation: the new law, the 2003 Act, the 2000 Act and the 2007 Act. There have also been calls, including from the Mental Welfare Commission, for a more wholesale review of the overall legislative framework for compulsory care and treatment.

As set out in the Introduction (Section 1), this review does not start with a predetermined outcome or process, and views are invited about what areas it should or should not cover.

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4. Questions on the scope of the review

4.1 The planned review of learning disability and autism in Scottish mental health law will help the Scottish Government consider whether new or amended legislation is required, or whether the current legislative framework should be retained in relation to people with learning disability and autism.

4.2 The previous two sections of this paper have identified some of the issues that the review might consider, and some of the changes that have taken place in Scotland (and internationally) which might have a bearing on what the review focuses on.

4.3 The Millan report (2001) suggested that a future review should consider:

- The implications for mental health law of changes in learning disability services
- The experiences of people with learning disabilities and autism who have been detained
- The arrangements that are needed for dealing with people with learning disabilities or autism who offend, or who are at risk of offending
- The experiences of other countries with alternative legislative frameworks.

4.4 The Scottish Government has specifically asked that the review additionally consider:

- The role of psychologists under the 2003 Act
- The use of psychotropic medication.

4.5 In the three questions below, you are invited to give your views on the issues that should be considered by the review.

⇒ To what extent are the suggestions made by Millan still relevant to consider in the review?

⇒ Are there any other issues you think the review should look at?

⇒ Are there any issues that you think the review should NOT look at?
5. How the review should be conducted

5.1 There are two questions to consider regarding the conduct of the review:

- How should the review be governed?
- What methods should be used for gathering evidence and consulting people?

5.2 This consultation seeks views in relation to both these questions.

Governance of the review

5.3 The first question is about who will be in charge of the review. There are a range of options. For example, recent national reviews and policy development exercises have been carried out by:

- A single independent individual with a small expert group of advisers (e.g. the Scottish Child Abuse Inquiry led by Susan O’Brien QC, or the Independent Advisory Group on Stop and Search led by John Scott QC)
- A group of representative experts (including experts by experience) with a chair appointed by Ministers (e.g. the Millan review or the recent Scottish Government review of public health)
- An independent body (such as MWC or SCLD) (e.g. as the Scottish Human Rights Commission oversaw the creation of the Scottish National Action Plan on Human Rights)
- A civil service team (e.g. the Fairer Scotland conversation).

5.4 Consultees are invited to give their views on the type of governance that would work best for the planned review.

Methods for gathering evidence and consulting people

5.5 When the Millan review was carried out in 1999–2000, it was undertaken using a fairly traditional model of policy development. This involved:

- The collection and analysis of written / published evidence
- A public consultation.

5.6 In fact, the Millan Committee carried out two public consultations – one at the beginning of the review and a second towards the end of the review – and separately engaged with a wide range of individuals and organisations in developing what was to become the Mental Health (Care and Treatment)(Scotland) Act 2003. The evidence gathering and consultation process included:

- A literature review
• Visits to 37 services and facilities, including advocacy and mutual support groups; forensic and secure mental health services; learning disability services; community based mental health services; psychiatric hospitals; a prison and a secure school
• Observations of Section 18 hearings in two Scottish sheriff courts
• Visits to Mental Health review tribunals in England
• Meetings with representatives of the Mental Welfare Commission
• Hearing oral evidence from 8 individual experts and representatives of 22 expert organisations
• Three consultation events for people who use mental health services and their families / carers
• Three special interest events focusing on dementia, learning disability and children
• Distribution (through mental health services across Scotland) of 11,000 copies of a ‘Have your say’ consultation leaflet for people with mental health problems and their families / carers.

5.7 The Millan review was notable for the extent of its engagement with stakeholders, and its efforts to build consensus among individuals / groups representing a wide range of views.

Good practice in engagement and consultation

5.8 In the years since the Millan review, there has been an increasing focus on public and service user participation in policy development, service planning and delivery. Such participative approaches are based on the principle that the people who are affected by a service / policy / initiative are best placed to decide how that service / policy / initiative should be delivered. These types of approaches are inclusive and transparent, are driven by ‘bottom-up’ rather than ‘top-down’ priorities, and would be consistent with Article 4 of the UN Convention on the Rights of Persons with Disabilities which states that: ‘countries must take a range of measures, with the active involvement of people with disabilities, to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind.’

5.9 Research carried out in 2011 by the National Council for Voluntary Organisations, the Institute for Volunteering Research, and Involve looked at how people participate in society.27 The study explored how and why people participate and how their participation changes over time. One of the recommendations from this report discussed how to improve public consultations to encourage greater participation, and proposed the following:

• Involve people early enough in decision-making cycles to be able to make a difference (not after the decision has been taken)
• Provide ways that people can participate that fit their everyday lives

• Provide a variety of options to allow people to participate in the way that suits them best
• Manage consultations so that people are asked for their views once on a topic, and not over and over again on similar issues
• Let participants know what difference their views have made, and how they are being taken into account
• Let participants know what the final decision is.

5.10 Other relevant good practice guides include:

• **The National Standards for Community Engagement** created by the Scottish Community Development Centre.\(^{28}\) This sets out 10 standards of best practice for engagement between communities and public agencies

• **The Charter for Involvement** developed by ARC Scotland’s National Involvement Network.\(^{29}\) This document sets out a series of 12 statements that show how people who use support services want to be involved: in the services they get, in the organisations that provide their services, and in the wider community. The charter was developed and written by people who use services.

5.11 In relation to consulting with people with ASD in particular, the National Autistic Society has highlighted the importance of:

• Gaining a good cross-section of opinions from people with autism, as some individuals may be focused on the issues that are currently affecting them
• Getting views from people across the whole autism spectrum
• Getting the views from people with autism and co-morbidities
• Getting facilitators who understand autism and how to support people to communicate their views
• Finding appropriate venues (big enough, with break-out rooms and quiet areas)\(^{30}\)

5.12 There have been a range of engagement exercises in recent years which show how such principles can be followed in gathering the views of different groups on different issues. Two examples are given below regarding recent consultations among people with learning disabilities and autism.

5.13 Consultees are invited to give their views on how the review would best be carried out.

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\(^{30}\) Taken from a presentation given to the National Autistic Society Conference, 2011, *Engaging and consulting with adults on the autism spectrum.*
Case study 1: Development of Phase 2 implementation plan for The Keys to Life – SCLD engagement events

To inform the development of Phase 2 of the implementation plan for Keys to Life, the Scottish Commission for Learning Disability held two half-day events for people with learning disabilities and autism, their families and carers, and the professionals who work with them. One event was held in Dundee and one in Stornoway.

Part of the purpose of the event was also to tell people about The Keys to Life.

Participants were invited to talk about their lives, how services were helping them, and what the gaps were. There was a recognition that it can sometimes be hard for people to talk about how they would like things to change, so much of the discussion was framed in terms of ‘What I like’ and ‘What I don’t like’.

To help prompt discussion, the events also made use of short films on topics such as friendship, hate crime, employment, etc. There were also presentations from invited speakers: self-advocacy groups, community theatre groups and sports practitioners.

People were invited to express their views in a range of ways:

- Using a ‘Wish Tree’ – people could write down their answer to the question: ‘If there was one thing you would like to be different, what would it be?’
- Using Clikapads, a system that allows people to vote using individual keypads – this system was used: (i) to establish (by way of a ‘Who Wants to be a Millionaire’ format quiz) what people knew at the start of the day about the Scottish Commission for Learning Disability and The Keys to Life; and (ii) to identify individuals’ opinions on a range of issues.
- Through small group discussions – people could write or draw on paper tablecloth.

The aim was to give people as many ways as possible to say what was important to them.
In August 2015, the Scottish Government began a national conversation with the people of Scotland about what a healthier Scotland would look like, and what steps could be taken to make that happen. More than 9,000 people took part in the conversation at 240 events over a six-month period.

SCLD facilitated three events for people with learning disabilities, their families, carers and professional supporters. In total, 49 people attended the events, of whom 25 were people with learning disabilities. At each event, people were asked three questions:

- What support do we need in Scotland to live healthier lives?
- What areas of health and social care matter most to you?
- Thinking about the future of health and social care services, where should our focus be?

To help participants to consider their responses and talk about their views, activities were planned on the theme of ‘health and wellbeing’:

- Activity 1: People were asked to select a picture relating to health and wellbeing and talk about what the image meant to them. This was followed by a group discussion where participants were asked to rank, in order of importance, the concepts shown in the pictures selected. Comments made during the conversations were recorded on a flipchart to ensure all input was captured.

- Activity 2: Participants were split into small groups and each group was asked to make a poster (using writing, drawing and craft) which showed what they need now to be healthy and well, and what they would need in the future to remain healthy or to become healthy. Participants were given paper shapes on which they could write or draw who helps them to keep healthy. Comments made during these discussions were recorded, either on the posters themselves or on flip charts along with other notes from the event. The eventual output (the poster) was less important to the findings of this consultation than the conversation that went on during its creation.

6. Questions about the conduct of the review

6.1 The previous section has outlined some of the governance models and methods used by other reviews and consultation exercises. This current consultation invites views about how the planned review of learning disability and autism in the Mental Health Act 2003 should be carried out.

6.2 In carrying out the full review, it will be important that the review is governed in a way that will give everyone confidence in the review’s findings. (See paragraph 5.3 above.) You are invited to give your views in relation to the governance of the review.

⇒ Do you have any suggestions about how the review should be governed or led? Please explain your answer.

6.3 The review should also be carried out in a way that allows all interested people and organisations to participate in a positive and meaningful way. (See paragraphs 5.5-5.12 above.)

6.4 You are invited to give your views about the methods the review should use for gathering evidence and consulting people.

⇒ What are your thoughts about how the review should gather evidence and consult people?

⇒ Which individuals / groups / organisations should be involved in the review?

⇒ Are there any practical issues that should be considered when deciding how the review should be carried out (for example, information requirements for different groups, format and location of meetings and events, etc)?

⇒ If you are aware of any other examples of good practice for engaging with different groups which might provide lessons for the review, please describe them briefly here.
7. Responding to this consultation

7.1 Responses to this consultation are invited by **9.30am on Monday 4 July**.

7.2 Please **submit your response online** at:


7.3 The consultation questionnaire is available in Word format from this same web address. This can be used to prepare your response, which can then be copied and pasted into the online response form.

7.4 If you are unable to use the online response form, you can also send your response (using the Word version of the questionnaire) by email to:

d.griesbach@griesbach-research.co.uk

7.5 Or by post to:

Griesbach & Associates (MWC/SCLD consultation)
7 Hazel Avenue
Crieff PH7 3ER

7.6 An Easy Read version of the discussion document and questions is available from the same web address above.

7.7 All the responses will be analysed by an independent researcher, Dawn Griesbach, (Griesbach & Associates).

Any questions?

7.8 If you have any questions about this consultation, please contact Dawn Griesbach (Email: d.griesbach@griesbach-research.co.uk or Tel: 01764 650378).