

Review of learning disability and autism in the Mental Health (Scotland) Act 2003:

Findings from a scoping exercise

December 2016

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Note about terminology

Throughout this report, the term '**autism**' will be used to refer to autistic spectrum disorders (ASD) or autistic spectrum conditions (ASC), including Asperger Syndrome. The terms '**autism**' and '**learning disability**' both cover a broad range of conditions.

The word '**participants**' is used to refer to all those individuals who took part in the scoping study – as survey respondents, interviewees or workshop attendees.

Abbreviations

The following abbreviations will be used throughout this document:

2003 Act: The Mental Health (Care and Treatment)(Scotland) Act 2003

MWC: The Mental Welfare Commission for Scotland

SCLD: The Scottish Commission for Learning Disability

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities.

Acknowledgements

The research for this scoping study was undertaken by Dawn Griesbach (Griesbach & Associates) and overseen by Colin McKay and Alison McRae (both Mental Welfare Commission for Scotland) and Chris Creegan (Scottish Commission for Learning Disability).

Conclusions and recommendations to the Scottish Government (in Chapter 6 of this report) were jointly developed and agreed by Colin McKay, Chris Creegan and Dawn Griesbach.

We would like to thank the following individuals for their assistance with this work: Lorne Berkley, Oonagh Brown, Karin Dowell, Jacki Gordon, Sarah McLuckie, Andy Miller, Alison Platts, Catriona Rowley, Claire Stuart, Susan Tait, Kathleen Taylor, Lily Waterton and Jamie Wilson.

We also give our sincere thanks to everyone who contributed their views, as survey respondents, interviewees or workshop participants.

1. Introduction

1.1 This report presents findings from a scoping study carried out by the Mental Welfare Commission for Scotland (MWC) and the Scottish Commission for Learning Disability (SCLD) on behalf of the Scottish Government. The purpose of the scoping exercise is to help lay the foundations for a review which will consider whether the provisions in the Mental Health (Care and Treatment) (Scotland) Act 2003 fulfil the needs of people with learning disability and autism

Background – the Millan Review

1.2 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 under which detention in hospital and / or compulsory treatment may be carried out, the legal protections for individuals in these circumstances, and 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.

1.3 The 2003 Act resulted from the work of the Millan Committee, which was set up in 1999 with a remit to review mental health law in Scotland, and which reported in 2001.¹ 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.

1.4 The arguments **against** inclusion were that:

- The 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 autism, which may be comorbid, are (usually) lifelong conditions, which cannot be cured or treated by medication. If a person with a learning disability or autism 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 autism.

¹ Millan Committee (2001), *New Directions: Report on the Review of Mental Health (Scotland) Act 1984*. Scottish Government: https://www.mhtscotland.gov.uk/mhts/files/Millan_Report_New_Directions.pdf.

- People with learning disabilities and autism are more likely to receive support from a psychologist, rather than a psychiatrist, to address any issues related to these conditions such as aggressive or distressed behaviour (sometimes referred to as ‘challenging behaviour’). However, the 2003 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 could result in people being detained in hospital for lengthy periods because the right community-based services are not available.
- The inclusion of learning disability and autism in mental health legislation was seen to contribute to the marginalisation of people with these conditions.

1.5 However, the **counter-arguments in favour** of including learning disability and autism in the 2003 Act were that:

- It is not uncommon for people with learning disabilities 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 somebody with a learning disability or autism 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 who behave inappropriately or commit a crime 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.

1.6 The Millan Committee ultimately recommended that (a) learning disability should be included in the new Act, and (b) learning disability should be considered to include autistic spectrum disorders. However, it also called for this arrangement to be reviewed at an early opportunity. The Millan Committee suggested that a future review should consider the following:

- The experiences of people with learning disabilities and autism who have been subject to compulsory interventions under the 2003 Act
- The arrangements that are needed for people with learning disabilities and autism who offend, or who are at risk of offending

- The experiences of other countries that have different arrangements in respect of compulsory care for people with learning disabilities or autism
- The implications for mental health law of changes in learning disability services (which have taken place since 2000).

1.7 Since the 2003 Act came into force, concerns about the inclusion of people with learning disabilities and autism have continued to be voiced and there have been repeated calls from some organisations in the learning disability and autism communities for the law to be reviewed and amended as it relates to people with these conditions. (See, for example, the '*Citizens' Grand Jury Report*' by People First (Scotland), pages 40-41.²)

Scottish Government commitment to a review

1.8 During the parliamentary debate on the Mental Health Bill (now the Mental Health (Scotland) Act 2015), the (then) Minister for Sport, Health Improvement and Mental Health, Jamie Hepburn committed the Scottish Government to undertake a review of the inclusion of learning disability and autism within the 2003 Act.³

1.9 It was noted that the review would not start with a pre-determined outcome or process, that stakeholders would be consulted before the remit and scope of the review were determined, and that the timescale for the review would not be constrained.

1.10 As a first stage in the review process, the Scottish Government asked the Mental Welfare Commission for Scotland (MWC) and the Scottish Commission for Learning Disability (SCLD) to undertake a small-scale scoping study to gather views from a range of stakeholders on three main issues:

- What should the scope of the review be? (In addition to the specific issue of the inclusion of learning disability and autism within the Act, the Government has already said that the review will consider the following issues: (i) the role of psychologists under the 2003 Act and (ii) the use of psychotropic medication.⁴)
- Who should be involved?
- How (and with what timescales) should the review be conducted?

² People First (Scotland) (2011) *Citizen's Grand Jury Report*: <http://peoplefirstscotland.org/jury/>. People First (Scotland) is a membership organisation open only to people with learning difficulties (a term it uses in preference to learning disability) and is run by its members.

³ See Official Report of the Scottish Parliament for 24 June 2015, columns 73 and 74 and columns 121 and 122: <http://www.parliament.scot/parliamentarybusiness/report.aspx?r=10037&mode=pdf>.

⁴ *Ibid.*, column 122.

1.11 The scoping study was intended to ensure that the full review addresses the things that are important to people, and that it is a meaningful and successful process for all involved.

Remainder of this report

1.12 The next chapter of this report describes the methods used to carry out the scoping study. Chapters 3 to 5 present the main findings of the scoping study and provide an analysis of the views expressed by those who took part.

- Chapter 3 discusses people's views in relation to the scope of the review
- Chapter 4 focuses on who should be involved in the review
- Chapter 5 discusses how the review should be conducted.

1.13 The final chapter (Chapter 6) draws some conclusions from the study and makes recommendations to the Scottish Government in proceeding with the review.

2. Scoping study methods

2.1 This chapter provides information about how the scoping study was carried out. As noted in the previous chapter, the scoping study sought to gather views on three main issues:

- What should the scope of the review be?
- Who should be involved?
- How (and with what timescales) should the review be conducted?

2.2 MWC and SCLD commissioned Dawn Griesbach (Griesbach & Associates) to undertake the research for the study.

2.3 Given the short timescales for the work, the objective was to consult key individuals and groups representing a diverse range of views – **not** to consult every individual, group and organisation that may have an interest or wish to participate in the wider review.

2.4 The scoping study was qualitative in nature. The purpose was to identify the range of views in relation to the three issues above, and to ascertain where there was agreement and disagreement among key stakeholders.

2.5 The work was carried out between May and September 2016 and involved three stages.

Stage 1: Survey of stakeholders (May / June 2016)

2.6 MWC and SCLD produced a discussion document which set out the context for the review. This document was accompanied by a survey containing eight open questions.⁵ The survey invited views on the three issues listed at paragraph 2.1 above (i.e. scope of the review; who should be involved; and how it should be conducted). A separate Easy Read discussion document and questionnaire were also produced with assistance from SCLD. Information about the scoping exercise and survey was circulated by MWC and SCLD through their networks and the discussion document and questionnaire were also made available on the MWC and SCLD websites. Respondents were invited to submit their views online (through Survey Monkey), or by email or post. The consultation period was short (six weeks), reflecting its status as a preliminary fact-finding exercise.

⁵ A copy of the consultation document is available from the Mental Welfare Commission upon request by email to: enquiries@mwscot.org.uk.

Response to the survey

2.7 The survey received 68 responses, of which five were excluded from the analysis. In four cases, this was because the respondent had submitted two identical responses – one by email and one using the online form. One further response was an amended version of an earlier response; the earlier response was removed and the later response was included in the analysis.

2.8 Thus, analysis was based on **63 responses**, 37 from individuals and 26 from organisations or groups (Table 2.1). One of the individual responses and two of the organisational / group responses were submitted using the Easy Read questionnaire.

Table 2.1: Number of responses to the survey

Respondent type	n	%
Individuals (including one Easy Read response)	37	59%
Organisations (including Easy Read responses from two groups)	26	41%
Total	63	100%

2.9 Organisational respondents comprised NHS bodies, local authorities and health and social care partnerships; third sector organisations; professional and regulatory bodies; and advocacy, campaign or service-user groups (Table 2.2). A complete list of organisational respondents is attached at Annex 1.

Table 2.2: Organisational respondents to the survey

Organisation type	n	%
NHS bodies, local authorities and health and social care partnerships*#	12	46%
Third sector organisations	6	23%
Professional / regulatory bodies	4	15%
Advocacy, campaign or service-user groups	4	15%
Total**	26	100%

* Includes two responses representing teams based across more than one organisation

Includes one response in which the respondent indicated she was also responding in her capacity as chair of two professional groups

** Percentages do not total 100% due to rounding.

2.10 Those completing the questionnaire in an individual capacity were asked to provide information about their interest in the review, and 34 of the 37 individual respondents did so. In 21 cases, respondents indicated a professional interest in that they worked in an NHS, local authority or voluntary sector organisation (one respondent reported multiple roles). In 12 cases respondents identified themselves as having a personal interest: i.e. they had a learning disability or autism (one person), or they were a parent / carer of a person with a learning disability or autism; in one case, the respondent indicated they were involved in a mental health group. One respondent with a personal interest in the issue also reported they were employed in the NHS, although it is not clear if this role was directly relevant to the issue under consideration. In three cases, respondents did not provide any information to enable further classification.

2.11 Not all respondents answered all the questions posed. Response rates ranged from 88% for Question 2 to 50% for Question 3. See Annex 1 for details.

Stage 2: Interviews with selected individuals / groups (June / July 2016)

2.12 A mix of telephone and face-to-face interviews were carried out with representatives of relevant organisations and groups to explore issues in more depth. Interviewees were chosen by MWC and SCLD to provide a range of perspectives and comprised representatives of relevant professional groups (including the Royal College of Psychiatrists, British Psychological Society, Social Work Scotland, Learning Disability Nursing Forum, Law Society of Scotland); organisations with specific duties under the 2003 Act (Mental Health Tribunal for Scotland); third sector organisations working with people with learning disabilities and autism; academic experts; and advocacy and campaign groups.

2.13 Altogether, 18 interviews were carried out. In some cases, interviews involved two or more people. In addition, two group discussions were held with: a) four representatives of People First and b) eleven members of the Scottish Government's 'Keys to Life' Expert Group.⁶ Annex 2 contains a list of the organisations / groups which took part in interviews.

⁶ The Scottish Government's Expert Group on Learning Disability. This is a group of 'experts by experience' who are supported by SCLD to provide advice and input to the Scottish Government on policies affecting people with learning disabilities.

Stage 3: Workshops (August / September 2016)

- 2.14 Following an analysis of the survey and interview data, two briefing papers were produced summarising the main findings. Briefing Paper 1 discussed findings in relation to the scope of the review and Briefing Paper 2 discussed findings in relation to the conduct of the review (including who should be involved in the review).
- 2.15 These two papers provided a basis for further discussion at two workshops held in Glasgow (August 2016) and Edinburgh (September 2016). The stated aim of the workshops was to explore specific issues in more depth. Attendees were invited to comment on preliminary conclusions about the scope of the review drawn from the findings of the survey and interviews. In addition, people's views on different aspects of the conduct of the review were explored further – particularly where the survey and interviews had identified a divergence in views.
- 2.16 The first workshop focused on autism and the second focused on learning disability. Workshop participants included both private individuals and those representing relevant organisations or groups. Participants were selected because of their personal or professional experience in relation to these conditions, and to ensure a range of views were represented. Some of the workshop participants had contributed to one or both of the earlier stages of the scoping exercise and some had not. Annex 2 includes a list of the organisations and groups represented at the workshops.

3. Views on the scope of the review

3.1 This chapter discusses participants' views about the scope of the review. Following on from the recommendations of the Millan Review (see paragraph 1.6 above), the survey asked three questions in relation to the scope of the review. These same questions were also put to all interviewees:

- To what extent are the suggestions made by Millan still relevant now?
- Are there any other issues the review should look at?
- Are there any issues that the review should NOT look at?

3.2 The main points raised by participants in relation to each of these questions are discussed below.

Need for the review

3.3 There was near unanimous agreement among survey respondents and interviewees about the need for a review of the 2003 Act as it concerns people with learning disabilities and autism. Moreover, the recommendations of the Millan Review were largely seen as still relevant.

3.4 People highlighted examples of inconsistent and (in the views of some) inappropriate application of the law in relation to these groups, and they voiced concerns about the increasing use of compulsory measures, and the duration of detentions for people with learning disabilities as compared to other groups detained under the 2003 Act. A specific concern was raised about compulsory treatment involving the use of psychotropic medication for people with autism.

3.5 There were also positive reasons given for having a review at this time – specifically:

- The review would offer an opportunity to ensure that mental health law in Scotland (and the treatment of people with learning disabilities and autism in particular) is consistent with international human rights law and the new benchmark provided by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁷ and
- The review would, potentially, provide the catalyst for a wider review of legislation concerning vulnerable adults and people who may lack the capacity to make decisions for themselves.

⁷ See <http://www.un.org/disabilities/convention/conventionfull.shtml>.

3.6 Most of the interviewees were aware of the arguments given by some organisations for removing learning disability from the 2003 Act. At the same time, it was noted that if learning disability and autism were removed from the 2003 Act, the number of people who would be directly affected by this change would be very small when compared to the total number of people with these conditions known to services. (See Box 1 below.) The point was made that these individuals were not subject to compulsory measures simply **because** they had a learning disability. Rather these individuals were likely to have complex and multiple care needs, communication difficulties, and a degree of risk (to themselves or others) which led to their detention in hospital.

Box 1: Number of people with learning disabilities and autism subject to compulsory measures

The last learning disability census carried out by the Mental Welfare Commission found that, in 2012, there were **351** people with a diagnosis of learning disability who were subject to some form of compulsory order under the 2003 Act. Of these, **88** also had a diagnosis of autistic spectrum disorder recorded on their forms. [1]

More recent statistics published by the Mental Welfare Commission for 2015/16 showed that, of the 4,098 Short Term Detention Certificates issued in that one year period, **190 (5%)** related to individuals with a learning disability, and **41 (just 1%)** had a diagnosis of **only** learning disability. [2]

In addition, research carried out for the Mental Welfare Commission in 2015 found that **260 people** with a learning disability diagnosis were subject to a compulsory treatment order on a single (census) date in August 2015. Of these, **83** had a learning disability with no additional diagnosis of mental illness or personality disorder. [Unpublished research]

These figures can be compared to statistics published by the Scottish Commission for Learning Disability which showed that, in 2015, there were **27,218 adults (over 16) with learning disabilities** and **4,617 adults on the autism spectrum** known to local authorities across Scotland. [3]

References:

[1] http://www.mwcscot.org.uk/media/139675/ld_census_2012.pdf

[2] www.mwcscot.org.uk/media/342871/mha_monitoring_report_to_omg_on_2_aug_2016_-_final_ab_19_sept_16_jw_26.09.pdf

[3] <http://www.sclid.org.uk/wp-content/uploads/2016/08/2015-Learning-Disability-Statistics-Scotland-report-1.pdf>

Treating learning disability and autism separately

3.7 Participants acknowledged that there is some overlap between learning disability and autism. However, they emphasised that the review should not conflate the two conditions. They argued that the needs of individuals with these two conditions are different, and the most appropriate response to those separate needs (legislative or otherwise) is also likely to be different.

The experiences of people who have been detained

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

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

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

3.10 One interviewee referred to research currently being carried by an international team led by Dr Eilíonóir Flynn at the National University of Ireland (NUI) Galway. The VOICES project (Voices of Individuals: Collectively Exploring Self-determination) is investigating how the use of supported decision-making might work in practice in relation to: (i) consent to medical treatment; (ii) criminal responsibility; (iii) contractual capacity; and (iv) consent to relationships / sex. The study has significant involvement from people with disabilities. It was suggested that this research may not

only provide an important source of evidence for the review, but may also offer lessons in how to involve people who have been subject to the 2003 Act in the review process. (See Box 2 for further information.)

Box 2: The VOICES project, led by NUI Galway

The project aims to address three questions which will help to frame a comprehensive approach to previously neglected aspects of legal capacity law reform. These questions are:

- What constitutes an exercise of legal agency from an individual?
- What are the justifiable limits on individual agency which can be imposed by the State and apply to everyone, regardless of disability or decision-making ability?
- How can we ascertain whether an individual is giving free and informed consent (necessary to make an action legally binding), without engaging in a functional assessment of that person's mental capacity?

The project involves pairing disabled people who have experience of one of the four areas listed in paragraph 3.10 above with experts from a range of professional backgrounds (legal, social work, academic, etc.) to work through their stories and consider what a supported decision-making solution might look like in their situations.

The project is due to complete in 2018, but the research team is publishing working papers on an ongoing basis. See: <https://ercvoices.com/>.

Learning disability and autism in the criminal justice system

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

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

and nature of restrictions placed on people with learning disabilities seem to be out of proportion to the offence committed.

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

- The reasons that people with learning disabilities and autism come in contact with the criminal justice system
- How the criminal justice system deals with these individuals (at arrest, in court, in prison) – specifically, the extent to which supported decision-making is being promoted in criminal justice contexts, and the provision of the ‘Appropriate Adult’ scheme in particular
- The long term outcomes for people with learning disabilities and autism who have been in contact with the criminal justice system since the 2003 Act came into force
- Whether people with learning disabilities and autism are disadvantaged in the criminal justice system as compared to other people
- The supports available to help people address their behaviour before it becomes a criminal justice matter.

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

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

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

The experiences of other jurisdictions

3.16 People agreed that the review should gather evidence about legislative arrangements in other countries relating to people with learning disabilities and autism, and there was particular interest in new legislation recently enacted in

Northern Ireland.⁸ People also wanted the review to consider the experience of New Zealand which has separate legislation related to learning disability.⁹ Others suggested that the review should gather evidence from:

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

The wider legislative context in Scotland

3.17 There was a repeated call among survey and interview participants for any legislative review **not** to focus narrowly on the question of whether learning disability and autism should (or should not) be removed from the 2003 Act. Rather people argued that a more comprehensive review of the wider legislative framework for non-consensual care and treatment in Scotland is now required.

3.18 People believed the scope of the review should, therefore, include not only the 2003 Act, but also the Adults with Incapacity (Scotland) Act 2000 and the Adult Support and Protection (Scotland) Act 2007. Some people also suggested that this wider review should encompass s13ZA of the Social Work (Scotland) Act 1968, the Social Care (Self-directed Support) (Scotland) Act 2013 and the Criminal Procedure (Scotland) Act 1995, part VI, as all of these include provisions which allow the State to take certain actions or make decisions on behalf of individuals who may lack capacity.

3.19 Participants offered the following arguments in support of a wider review:

- Current legislation in this area is very complex. Some suggested that the different Acts had ‘got out of step with each other’, and the review should consider whether there was scope for ‘rationalisation’.
- There were specific concerns about the use of guardianship and power of attorney, which are covered within adults with incapacity legislation, but which

⁸ Mental Capacity Act (Northern Ireland) 2016: <http://www.legislation.gov.uk/nia/2016/18/contents/enacted>

⁹ See <https://www.health.govt.nz/system/files/documents/publications/idccrguidelines-intellectualdisability.pdf>

also have an impact on the rights of people with learning disabilities and autism. Specifically, people had concerns about: (i) the length of time between reviews of guardianship arrangements for people with learning disabilities or autism; and (ii) the extent to which these individuals are involved in these reviews. It was also noted that the process for applying for guardianship involved a different judicial body (the sheriff court rather than the Mental Health Tribunal) and different procedures than the process of applying for a compulsory treatment order.

- The review should consider the full range of support which people with learning disabilities and autism may need. It would be more difficult to do this if the review looks **only** at the 2003 Act in isolation.

3.20 There were also arguments against focusing **only** on learning disability and autism. For example:

- A narrow focus on learning disability and autism and the definition of ‘mental disorder’ was seen as a ‘piecemeal’ approach to addressing more significant issues related to compulsory treatment, restriction of liberty and substitute vs supported decision-making.
- People considered that legislation based on particular diagnoses was problematic. The issues that this review will consider for people with learning disabilities and autism may also apply to people with dementia, mental illness, personality disorder and other conditions.¹⁰

3.21 People thought that a wider review would be very challenging and would require significantly more time than had been envisaged for a review of learning disability and autism in the 2003 Act. However, they also thought it would offer the opportunity to take a fresh look at Scotland’s mental health and incapacity legislation, and to reframe it to take account of current standards in human rights and the UNCRPD. Participants suggested that the extensive work carried out for the Bamford Review in Northern Ireland, which provided the basis for the Mental Capacity (Northern Ireland) Act 2016, could offer a useful starting point.

3.22 There was also a suggestion that, in setting the scope of the review, it might be helpful to refer to a written response made by the Council of Europe’s Commissioner on Human Rights to the Oviedo Convention¹¹ regarding a draft ‘Additional Protocol’

¹⁰ Examples given were Acquired Brain Injury, Attention Deficit Hyperactivity Disorder (ADHD), Prader-Willi Syndrome and Lesch-Nyhan Syndrome.

¹¹ An international convention concerned with the protection of human rights in the field of biomedicine.

on involuntary placement and involuntary treatment of persons with mental disorders.¹² The Commissioner's comments included suggestions about how to move away from the use of coercion in psychiatry, and towards greater protection from discrimination for people with psychosocial disabilities¹³ by focusing on the identification of good practice in relation to:

- Developing non-discriminatory criteria for assessing risk to self or others, as well as impairment of decision-making capacity
- Promoting alternative measures and reducing recourse to coercion in psychiatry, as well as reducing excessive use of restraints or medication
- Involving patients in treatment decisions and ensuring access to adequate support for decision-making for people with psychosocial disabilities.

Other aspects of the 2003 Act which the review should consider

3.23 Notwithstanding the frequent calls for a comprehensive review of current mental health and incapacity legislation in Scotland, participants in the scoping study were nevertheless also keen that the review should not lose sight of the particular needs of people with learning disabilities and autism. They highlighted a range of other issues related to the 2003 Act which the review should consider in relation to these groups.

Terminology and definitions

3.24 People often explicitly stated that they did not consider learning disability and autism to be 'mental disorders', and that these conditions should not be included within the definition of 'mental disorder' under the 2003 Act. This view was expressed not only by people with learning disabilities and autism, family carers and advocacy groups, but also by professional care providers. Different individuals suggested that more suitable terms might include 'long term condition', 'disability' or 'disorder of mental development', but there was not consensus about any alternative terminology.

3.25 An alternative, though less common view was that the issue of definitions was not the most important point to consider. Those who held this view acknowledged and understood the arguments for removing learning disability from the definition of

¹² The full title of the draft 'Additional Protocol' was: *Working document concerning the protection of human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment.*

¹³ See paragraph 35 of the comments from the Council of Europe Commissioner for Human Rights, 9 November 2015:
<https://wcd.coe.int/ViewDoc.jsp?p=&id=2394367&Site=COE&BackColorInternet=DBDCF2&BackColorIntranet=FDC864&BackColorLogged=FDC864&direct=true>

‘mental disorder’. However, they did not believe these arguments justified the removal of learning disability from the 2003 Act. Rather this group thought the important questions for the review were about: a) whether the provisions of the 2003 Act related to compulsory care and treatment represented the right approach to take with individuals who had impaired decision-making and were at risk of harming themselves or others, or b) whether there was a better approach which should be used instead.

3.26 In relation to autism, the issue of ‘definition’ is more complicated. The Millan Review recommended that autism be included within the meaning of learning disability, but the Act itself makes no direct reference to the condition. This has caused confusion in applying the Act, particularly in relation to people with Asperger Syndrome whose condition affects their social functioning, but not their ability to make decisions.

The Millan principles

3.27 The 2003 Act is underpinned by a set of 10 principles which set out how professionals should work when providing care and treatment under the Act. It was suggested that the review should revisit these principles to determine: (a) whether they are acting as a guide to practice in the care and treatment of people with learning disabilities and autism (as intended), or (b) whether they need to be changed to better reflect current standards in human rights and the UNCRPD.

The role of psychologists (and other professionals) in the 2003 Act

3.28 There was support for the idea that the review should consider a possible role for psychologists in carrying out treatment under the 2003 Act. Psychologists were seen to have the necessary skills and knowledge of Positive Behavioural Support interventions to be able to take on the role of ‘Responsible Clinician’, and it was suggested that the review should identify what additional competencies psychologists would need to fulfil any new responsibilities relating to the use of compulsory measures.

3.29 However, there were also different perspectives on the **current** role of psychologists in supporting people with learning disabilities and autism, and it was pointed out that there were differences across Scotland in the availability and involvement of psychologists in multiagency learning disability teams.

3.30 Speech and language therapists were also reported to have an important role in providing care and support to people with learning disabilities and autism – particularly where the individual was ‘non-verbal’ or had other communication

difficulties. It was suggested that the review should consider whether speech and language therapists should have a role within a legislative framework to assist with supported decision-making.

3.31 A view was also expressed among some participants that the 2003 Act gives psychiatrists 'too much power' and that the recommendations of psychiatrists (regarding compulsory treatment) are often carried even where a Mental Health Officer disagrees.

Advocacy services for people with learning disabilities and autism

3.32 People thought the review should examine the extent to which independent advocacy is available to, and used by, people with learning disabilities and autism who are subject to the 2003 Act, and consider whether there should be standards for advocacy services in working with these groups. People reported both positive and negative experiences of advocacy services being used by people with learning disabilities and autism.

Psychotropic medication

3.33 The use of psychotropic medication to treat behavioural problems in people with learning disabilities and autism was a serious concern for some people, and there were calls for the review to examine: how and when medication is prescribed; whether it is being used appropriately (there were particular concerns about the possible use of medication as a 'chemical restraint'); the extent to which current prescribing practice (particularly in relation to people with autism) is consistent with NICE guidelines¹⁴; what strategies are used for stopping medication when it is no longer needed; and whether the use of medication increases suicidal behaviour among people with learning disabilities and autism.

Other issues

3.34 People raised a range of other issues concerning the 2003 Act which they suggested the review should examine, including:

- Whether and how people are supported to make decisions about having a 'named person'¹⁵

¹⁴ See <https://pathways.nice.org.uk/pathways/autism-spectrum-disorder>

¹⁵ A 'named person' is someone who can help to protect the interests of a person who has to be given care or treatment under the 2003 Act. The named person will have to be informed and consulted about aspects of the person's care and can make certain applications on the person's behalf. See <http://www.gov.scot/resource/doc/26350/0012825.pdf>

- Whether individuals with a wider range of expertise (e.g. neurologists, immunologists, etc.) should be part of tribunals in Mental Health Tribunal cases where the individual has autism
- Whether additional safeguards are needed for non-pharmacological interventions under the 2003 Act.

Service provision

3.35 The fourth topic suggested by the Millan Committee for consideration by any future review related to service provision. At the time of the Millan Review, learning disability services were undergoing a major transformation as long stay hospitals closed and people moved into the community. The majority of people with learning disabilities are now supported in the community, rather than in hospitals or other institutions. However, at the time of the Millan Review, fewer alternatives to in-patient services were available to those not being cared for by their families. This was one of the reasons that the Millan Committee recommended the inclusion of learning disability and autism in the 2003 Act, while also recommending an early review of these arrangements.

3.36 The people taking part in the scoping study raised a wide range of issues related to service provision. In general, they thought that the review should not focus solely on **legislation** and the way in which legislation is being used; it should also consider the way in which services are delivered – before, during and after an episode of compulsory care and treatment. In particular, people commented that:

- High quality, appropriate care and support are the key factors that enable a person to live independently in the community or to move back to the community after a period in hospital.
- The use of compulsory measures may result where there has been a breakdown in care and support in the community. The care and support of people with learning disabilities and autism requires integrated teams with specialist expertise; breakdowns in care and support were thought to happen where staff do not have the necessary skills and knowledge to provide good quality care. Stressed and distressed behaviour may also be an indication of inappropriate service provision.
- Stressed and distressed behaviour may become worse if a person is removed from their home and taken into hospital, and cannot understand the reason for this. This makes the assessment of these individuals more difficult.
- The length of detentions in hospital may be due to a lack of resources for more appropriate (less restrictive) support in the community and, related to this, a

reluctance by community services to accept the risks associated with caring for people with very complex needs.

- Out of area placements for people with complex needs are still too common.
- There is a dearth of assessment services for people with autism across Scotland, and problems with misdiagnosis (e.g. Asperger Syndrome being diagnosed as a personality disorder). The lack of a diagnosis or a misdiagnosis means that people are left unsupported. This can result in the development of mental health problems or offending, which can in turn lead to the use of compulsory treatment or imprisonment.
- Early onset dementia among people with Down's Syndrome often results in these individuals being inappropriately placed into care homes with adults who are much older. There was also a question about whether people with Down's Syndrome were being misdiagnosed with early onset dementia without adequate investigation of other possible causes of changes to their behaviour or cognitive abilities.
- The physical health needs of people with learning disabilities and autism are often overlooked, untreated, or seen as untreatable because they are attributed to these conditions (i.e. the learning disability or the autism).

3.37 At the same time, the point was also made that there is a great deal of good practice in Scotland with, for example, specialist integrated learning disability teams supporting people to live independently in their communities. Participants wanted the review to consider the factors that support good practice in this area.

Issues the review should NOT consider

3.38 Few people took the opportunity to comment on what the review should NOT consider. Among those who did, there was a view that the 2003 Act was a good piece of legislation which appeared to be working well for people with mental illnesses. This group thought it was unnecessary for the review to include any of the other groups covered by the Act. (Note, however, that the more prevalent view was that the findings of any review of the 2003 Act in relation to people with learning disabilities and autism would likely also be relevant to people with mental illness and personality disorder, and that changes to the legislation should take this into account.)

Workshop discussions on the scope of the review

3.39 Based on the information gathered from survey respondents and interviewees in stages 1 and 2 of scoping study, a preliminary proposal regarding the scope of the

review was drafted. This included seven questions which, it was suggested, the review might address. Attendees at both the workshops were asked whether these were the **main** questions the review should answer:

- Do we need to change the 2003 Act for people with learning disabilities and autism to take account of laws on human rights (including the United Nations Convention on the Rights of Persons with Disabilities)?
- Are the principles of the 2003 Act relevant to learning disability and autism, or should the principles be updated or changed?
- Do people with learning disabilities or autism need different kinds of protections when they must be taken into hospital or given medication when they do not want it? Do people with learning disabilities or autism need special protection in the law if they have to be physically stopped from hurting themselves or others, or kept separate from other people?
- Who should be involved in making decisions about treatment where people do not or cannot agree to it?
- What is the best way to help people with learning disabilities and autism who break the law, or who are at risk of breaking the law?
- What role should 'supported decision-making' have in the care and treatment of people who do not or cannot agree to their care or treatment?
- How can the law help people with learning disabilities and autism to have access to the right services to help them live independently?

Views of workshop attendees about the scope of the review

3.40 There were mixed views among workshop attendees that the questions above were the right questions for the review to focus on. The more dominant view was that they **were**, and discussions often focused on the specific issues that should be explored when addressing each question. However, workshop attendees with lived experience did not all agree with this. Some argued that the review should start with the fundamental question of whether learning disability and autism should continue to be included in the 2003 Act or removed from it. If it is agreed that they should be removed, then the purpose of the review should be to consider what other legislative framework (if any) would be required instead. Among this group, there was a view that existing mental health legislation was discriminatory and did not comply with current human rights standards. Thus, the questions above regarding substitute decision-making, or the protections required for people who are given treatment that they do not want were not accepted as appropriate for the review. It was argued that these questions assume that it is acceptable to make decisions on behalf of people

with learning disabilities and autism rather than provide people with the support to allow choices to be made which respect their will and preference.

3.41 Some workshop attendees thought there should be separate laws for learning disability and autism, and that the task of the review should be to consider what those laws would look like. However, the more common view was that mental health and capacity legislation in Scotland was already too complex and needed to be rationalised. Workshop attendees who worked as health and care providers across different sectors were particularly concerned that if separate laws were created for people with learning disabilities and autism, this might then lead to new laws being created for a wide range of other conditions as well, and this was seen to be untenable. This group also argued that, given the high levels of comorbidity between learning disability, autism and mental illness, it would not be helpful to create separate legislation for these conditions as this would mean that some individuals could be subject to multiple laws.

The issues of terminology and diagnosis

3.42 The term 'mental disorder' was universally disliked among workshop attendees. Those with lived experience of learning disability or autism commented that 'there is an assumption that 'disorder' resides within the person' whereas a more correct assessment would be that people with learning disabilities or autism often come into contact with services because of a crisis resulting from external factors over which they have no control. It was suggested that the review should begin by acknowledging that terminology and language are important. (It was noted that people with mental illnesses also dislike the term 'mental disorder'.)

3.43 The issue of 'diagnosis' arose as a significant and recurring theme in the autism workshop. One view was that it would be good to move away entirely from legislation based on diagnosis and labels. However, in relation to autism, there was not complete agreement about this. A range of (sometimes divergent) points were made:

- There were concerns that people with autism may be subject to the 2003 Act unnecessarily and given inappropriate treatment, because aspects of autistic behaviour may appear like mental illness. Before any decision is made to detain or treat someone under the 2003 Act, safeguards should be in place to ensure that the person has received the right diagnosis.
- It was noted that there is a high prevalence of learning disability among people with autism. People with autism also suffer from high levels of mental illness. The process of diagnosing these different conditions – particularly in an individual who is non-verbal – is extremely complex.

- There was a view that misdiagnosis was common. This was attributed by some to a lack of competence and skills in relation to autism among mental health professionals. There was also a view that the symptoms of underlying physical conditions were also sometimes being misdiagnosed as autism – or as mental illness among people with autism.
- There were concerns about the lack of diagnostic services across Scotland in general, and repeated concerns about the lack of specialist support available to people with autism even where a diagnosis has been confirmed.
- While some workshop attendees believed that labelling people with a diagnosis was unhelpful (particularly in light of the frequency of misdiagnosis and the potential for inappropriate treatment to be given on the basis of a misdiagnosis), others with lived experience of autism emphasised how vital it was for them as adults to have a diagnosis as this allowed them to understand themselves better and obtain support.

4. Who should be involved in the review?

4.1 The second question the scoping study invited views about was: who should be involved in the review. This question was explored in the survey and interviews, and an analysis of the findings was then presented to attendees at both the workshops.

4.2 There was broad agreement among different stakeholders in relation to this question.

4.3 People thought that the review should be inclusive and gather views from **ALL** perspectives and there was a great deal of consensus about the types of individuals, groups or organisations who should be involved in the review. These were:

- **People with learning disabilities and autism who have been subject to the 2003 Act:** There was a general view that the experiences and views of these individuals should be at the heart of the review.
- **Family carers** (or 'Named Persons' or guardians): The perspectives of these individuals were also thought to be crucial, particularly in cases where there may be challenges in obtaining the views of the person they care for (due to communication difficulties).
- **People with learning disabilities and autism who have NOT had direct experience of the 2003 Act:** The point was made that the review needs to consider the views of all people with learning disabilities and autism since the current legislation – and any future legislation – has the **potential** to have an impact on them. This group would include those who are not in contact with any support services.
- **Young people:** People commented that the views of older people with learning disabilities may be influenced by their experiences of institutional care prior to the closure of long-stay hospitals. Younger people with learning disabilities today do not have these experiences, and most have always lived in their own communities. Their views about compulsory care and treatment may therefore be different to those of older people.
- **Professionals with a role in the 2003 Act:** This group includes: psychiatrists, mental health officers / social workers, independent advocacy workers, staff and members of the Mental Health Tribunal for Scotland, and representatives of the Mental Welfare Commission.
- **Professional care and support providers:** This group includes the full range of individuals involved in the planning, delivery and regulation of health, social care and support services for people with learning disabilities and autism. It

includes people working in NHS, local authority, third sector and private sector care services.

- **Other experts:** These include academics and researchers, experts in law and human rights, individuals with knowledge and / or experience of legislative arrangements in other countries, and organisations that hold data or other information relevant to the review.

4.4 People talked about the importance of the review hearing from **everyone**. They thought it was crucial that the review consulted widely to ensure that the views it receives are truly representative of the wider learning disability and autism communities. In particular, it was suggested that the views of those who have campaigned for a change in the law in this area, while entirely valid, may not be representative of the views of all people, and particularly those with learning disabilities and autism who are most likely to be subject to the 2003 Act. Furthermore, the people most likely to be subject to the Act are also those who may have the greatest difficulties in making their views known – particularly where they have complex communication support needs.

4.5 Annex 3 contains a list of specific organisations participants suggested should be involved in the review.

4.6 Attendees at the workshops were asked to comment on the list given in paragraph 4.3 above. In general, there was consensus that these were the right groups of people to be involved in the review. However, further additional suggestions included:

- **People who do not use speech as a means of communication:** It was suggested that those who support these individuals would be able to provide assistance with communication.
- **People from black and minority ethnic groups:** This would include both those who have a learning disability or autism and their parents / carers.
- **People with learning disabilities and autism who have had experience of the criminal justice system**
- **The general public.**

4.7 Workshop participants made the following additional points:

- It is crucial that people with learning disabilities and autism are involved throughout the review – and their participation should be meaningful and not tokenistic.

- The population of people with learning disabilities and autism (and their families) in Scotland is a very diverse group of people. This diversity needs to be captured.
- There is a distinct group of people with autism who do not have a learning disability and these people should be consulted, whether or not they have had direct experience of the 2003 Act.
- Finding out about the **experiences** of people who have been affected by the 2003 Act (i.e. gathering qualitative evidence) is particularly important.
- The review should seek views from people living in both rural and urban areas.
- In obtaining the views of professional care providers, the emphasis should be on the views of those in 'front line roles'.
- The review should take stock towards the end of its work to determine whether any groups have been inadvertently excluded from participation, and then focus its attention on those groups.

5. How should the review be conducted?

5.1 The third question for which the scoping study sought to gather views was in relation to how the review should be conducted. Different aspects of this question were explored with participants. Specifically, survey respondents and interviewees were asked about:

- What the governance arrangements for the review should be
- How the review should gather evidence and consult people
- Whether there are any practical issues (for example, information requirements, format and location of meetings and events, etc.) that the review needs to consider
- Whether there are any examples of good practice for engaging with different groups that could inform the way the review is conducted.

5.2 The main points made by participants are summarised below.

Governance arrangements

5.3 In general, people thought the review should be led by a chairperson supported by a group of some kind. The involvement of the wider group was seen to be important as a way of providing 'checks and balances' to the review process. However, there were different views about the size and composition of the group.

Chairperson(s) of the review

5.4 People usually saw the review as having a chairperson, and thought the chairperson should be someone who was:

- Independent (i.e. from all interested stakeholders and from government), impartial, non-judgemental, and willing to listen to all points of view
- Clear thinking, analytical and rigorous
- Respectful of diversity, and knowledgeable about equality and human rights issues
- Able to get the job done.

5.5 People usually said that these qualities were more important in a chairperson than their knowledge of learning disability, autism, or mental health legislation. Indeed, some thought that anyone with a deep understanding of these areas might not be seen as being independent. However, others had a different view and thought it could be helpful for the chairperson to have some prior knowledge of the issues under consideration.

5.6 This issue was discussed further with attendees at the first workshop in an attempt to reach some consensus about whether people would prefer the chair to have expertise in this area or not. However, again, there was no clear agreement about this. While some people thought that relevant knowledge or expertise in learning disability / autism would be an advantage, there was also a view that *‘there is a different set of issues for autism and learning disability’* and so it may not be possible to identify a person who would have the necessary knowledge or expertise in both. The point was also raised again that any ‘expert’ in this area might not be seen as sufficiently independent. There was general agreement among workshop attendees that other qualities in the chairperson may be **more** important than specialist knowledge of the subject – particularly as there was agreement that the chair should not be someone from one of the stakeholder professions. Chairing skills, authority, credibility, insight, openness and independence were all identified as important qualities for the chairperson.

5.7 Occasionally, people suggested particular individuals or organisations whom they felt would be well placed to lead the review.¹⁶ More often, people made suggestions about the type of person who might have the qualities listed above. These included: an ‘academic’, a ‘senior member of the judiciary in Scotland’, ‘someone with a background in human rights’ or ‘someone from the field of medical ethics’. Other suggestions were that the review should be led by ‘an independent non-governmental organisation’ or ‘an independent advocacy organisation’.

5.8 Less often, people identified the sorts of individuals who they thought should **not** lead the review, including: a psychiatrist or other doctor / clinician, a civil servant, or (in contrast to the view above) a member of the judiciary or legal system. The different participants who made these comments all believed that individuals in these groups would not be perceived as being independent enough to lead the review.

5.9 There was also a suggestion that the review should have two co-chairpersons – one of whom would be an individual with a learning disability who should have support throughout the process to assist their involvement in the review. However, there was not strong support for this idea. Several difficulties were identified:

- If one of the co-chairs was a person with learning disability, then there should also be a third co-chair who was a person with autism. Such an arrangement was thought to be impractical.

¹⁶ These suggestions have been provided separately to the Scottish Government.

- Having more than one chairperson might cause confusion about the leadership of the process.
- An arrangement involving co-chairpersons could lead to stalemate in certain situations or compromises being made that do not result in the best decisions.

Review group

5.10 There were differences of opinion regarding the membership of the review group (or committee). The two most common views were that:

- It should be a small group of **experts** (including experts by experience)
- It should include **representatives** of all the various stakeholder groups (for example, people with learning disabilities and autism, family carers, psychiatrists, social workers, public, private and third sector health and social care organisations, law organisations, advocacy groups, civil servants, etc.)

5.11 These two views were not necessarily mutually exclusive, and some people talked about having ‘a group of representative experts’. At the same time, people thought it was important that the review committee should not be so large as to make it impossible for decisions to be made.

5.12 Some people saw the review group as being similar to the Millan Committee. Less common (contrasting) suggestions were that: a) the review should be led jointly by professional experts and people with learning disabilities and autism, or b) there should be a small group of ‘specialist advisors’ supporting the chairperson. There was also a view that the review group should be kept very small, given the particularly complex nature of the issue under consideration and the potential for strong disagreement among stakeholders. There were also concerns that non-representative, minority views should not dominate decision-making.

5.13 Given the wide diversity of views about the size, composition and role of the review group, this issue was discussed further at the first workshop. It was suggested that an ‘ideal arrangement’ would involve: a single chairperson with a core group of advisors (possibly around six people), and a wider reference group (or groups) which could be consulted about specific issues. The core group should comprise people who would inspire confidence among wider stakeholder groups. The reference group (or groups, since there may need to be separate groups for autism and learning disability) should include ‘experts by experience’ – i.e. people with learning disabilities and autism and parents / carers. Members of the reference groups could be identified through groups that work with people with learning disabilities and autism, or their carers, from around Scotland. There was also a suggestion that,

rather than **creating** reference groups, it may be preferable to engage with **existing** groups, which would allow people to give their views in a more relaxed and familiar setting.

Governance principles

5.14 As well as commenting specifically about the leadership and governance arrangements they would like to see put in place, participants also discussed the principles which they thought should underpin the review. These included that:

- The review should be open and transparent.
- The review should be independent – of the government, elected representatives and the civil service – and should not be hindered in its work by short-term political agendas and interests.
- The review should be fair and impartial in its work. It should consider all perspectives equally, and ensure that non-representative, minority voices do not dominate.
- The review should adopt a human rights based approach, and be guided by the principles of equality, diversity and respect.
- The review should be inclusive and collaborative in its approach – those involved and particularly those affected by the legislation should have an opportunity to comment on the findings, and to help shape the recommendations.

5.15 Individual respondents to the survey emphasised the importance of providing resources to enable participation by members of the review group who were not involved in a professional (paid) capacity.

What should the review do? Gathering evidence and consulting people

5.16 People generally envisaged the review process as involving two stages of: (i) gathering evidence and consulting people, and (ii) deliberation and decision-making. This latter stage may then lead to further consultation, particularly in relation to any recommendations made.

The review process

5.17 A few people made specific suggestions about the general approach which should be adopted in carrying out the review. As noted above, one suggestion was that it

should adopt an explicit human rights approach. The way of doing this in practice might involve use of the FAIR process¹⁷, and adopting the PANEL principles.¹⁸

5.18 A few people described review processes that they had seen used in relation to other topics. For example:

- **The indaba process:** This process would allow for participation by everyone who has something to say. However, decision-making would rest with a smaller group of 'leaders' (a kind of independent panel of experts), and this group would have the task of sifting through the statements made by all the participants.
- **The InterAction process:** This process would involve bringing together, around the same table, a roughly equal number of people who: a) are affected by the 2003 Act, or their representatives, and b) have legal responsibilities in relation to the 2003 Act. Support could be built in to ensure that everyone is able to contribute fully and work together to find solutions.

Gathering evidence

5.19 Chapter 3 of this report set out the wide range of issues people wanted the review to consider and for which it will need to gather evidence. Workshop participants were invited to suggest any other sources of evidence that the review should consider.

5.20 They emphasised the importance of the review having access to up-to-date statistics and any other existing relevant data and research evidence. However, it was also noted that there is, in fact, very little data collected by local authorities or NHS organisations in relation to the care and treatment (or care and treatment needs) of people with learning disabilities and autism.

5.21 Other possible sources of evidence could include:

- The Mental Welfare Commission, particularly in relation to its programme of visits and its role in monitoring the use of the 2003 Act.
- Health and social care integrated boards across Scotland – there was a question about the extent to which support for people with learning disabilities and autism was on their agendas.

¹⁷ See www.scottishhumanrights.com/careaboutrights/flowchart for further information about how to design a FAIR process.

¹⁸ See <http://www.scottishhumanrights.com/careaboutrights/whatisahumanrightsbasedapproach> for information about the PANEL principles.

- The NHS complaints procedure (possibly accessible via Freedom of Information requests), and the Scottish Public Services Ombudsman.

5.22 There was a clear consensus that one of the main things the review should gather evidence about is the **experiences** of people with learning disabilities and autism who have been detained or compulsorily treated under the 2003 Act. People often suggested that it would be helpful to carry out case studies focusing on a sample of these individuals. A case study approach would involve not only engaging directly with these individuals and their families and carers, but also gathering information from service providers about the nature of the care and treatment provided, how this has changed over time and why, whether other less restrictive forms of care were considered, what options were available for less restrictive care, etc. (See paragraph 3.8 above.)

5.23 People wanted the review to ‘get all sides of the story’, and there was a question about how evidence could be challenged if there were concerns about its validity.

Methods of consulting people

5.24 In relation to the process of consulting people, participants emphasised the need for the review to be wide ranging, inclusive, or ‘bottom-up’ in its approach to involving different individuals and organisations. There were several recurring messages:

- It is important that the review make every effort to consult widely among people with learning disabilities and autism and their families and carers. Representatives of all groups with an interest should be involved from the outset in shaping the process to ensure this was achieved. (Several of those who participated in this scoping study have offered their help with this.)
- A wide range of methods should be used to consult people – and a very wide range of specific methods was suggested. (See Annex 4 for details.) People should be given choices so they can participate in ways that are meaningful and comfortable to them.
- The review will need to give careful consideration to accessibility issues including: the location and timing of meetings and events; the format of events; and the need to reimburse expenses for those whose participation might involve travel and other costs. Environmental factors (venues should have disabled access and offer quiet spaces particularly for people with autism) and the information and communication requirements of different individuals (e.g. the use of Easy Read, Talking Mats, ipads, video, theatre, internet, etc.) were also highlighted. (See Annex 4.)

- It is important to consult carers and family members, particularly (but not only) carers and family members of those with complex / profound disabilities or communication difficulties. It was noted that it would be impossible for many family carers to attend events held in the daytime during the working week. Evening or weekend events, individual interviews, or surveys (online and paper) were considered to be possible alternative methods for obtaining the views of these groups.
- There were calls for the review to commission or work in partnership with appropriately skilled and experienced organisations in designing and / or delivering events and other review activities.

5.25 People emphasised the importance of providing support to people with learning disabilities and autism to allow them to participate fully in the review, with most discussing this issue in the context of face-to-face meetings and events. Support would be needed to help people understand and consider concepts and ideas (in preparation for and during events) and to help them develop and contribute their own views. Two issues were identified: (i) the challenge of ensuring that the views obtained were those of the individual, rather than those of their parent, carer or supporter; and (ii) the tendency that people may have to simply agree with strongly held views expressed by other people around them.

5.26 In a few instances survey respondents cautioned **against** the use of particular methods: one respondent questioned the reliability and efficacy of Easy Read questionnaires when used with those with learning disabilities (this view was, however, in contrast to those of people with learning disabilities who strongly advocated the use of Easy Read); another suggested that focus groups may be stressful for some participants.

5.27 A range of examples of good practice for involving people in policy-making and decision-making were offered by several survey respondents. This information has been collated at Annex 5 for reference.

5.28 Participants in the first workshop suggested that the use of social media might be particularly useful for making contact with and consulting groups within the autism community. Participants in the second workshop thought that consulting people with learning disabilities in small groups (face-to-face) in friendly environments would work best. In addition, people will need to be given assurances that their contributions will not affect their future care, treatment or career progression.

5.29 Participants in both workshops were specifically asked for their thoughts on how the review could reach people who **may not be connected to services, advocacy**

groups or campaigns. People agreed that it would be important for the review to try to engage with people (both those with learning disabilities and autism, and their families) who may not be in contact with services.

5.30 They suggested that this might be done through:

- GPs and health centres
- Occupational therapy services (people who are not in contact with other types of services may come in contact with hospital services)
- Social media
- Local authority records of guardianship orders
- Schools and further / higher education institutions
- Community events and social groups
- Informal support groups
- Word of mouth.

5.31 There was a view that the review should include a media (and social media) campaign to target people not connected to services or other groups.

Weighing the evidence

5.32 Participants recognised that there were some strongly held views in relation to the subject of the review. Some commented on the importance of finding a way to assess the divergent views of different groups, and there was a suggestion that the review may need to consider how different views might be 'weighted'. Some argued that the views of individuals and their carers should be given prominence, while others were concerned that strongly expressed minority views should not dominate the process. There was also a suggestion that the review should seek to 'triangulate' views from different perspectives.

Timescales for the review

5.33 During the parliamentary debate on the Mental Health Bill, it was proposed that the timescale for the review should be three years from the date of royal assent (4 August 2015). However, while this timescale was thought to be reasonable, no specific commitment was made in relation to the timescale for the review because the (then) Minister for Sport, Health Improvement and Mental Health felt it was important to consult with stakeholders about the scope of the review first, before setting a timescale.

5.34 In the meantime, the Scottish Government has proposed that the review should start 'by April 2017'.¹⁹

5.35 Neither the survey nor the interviews explicitly explored the issue of the timescales for the review. However, people often raised the issue spontaneously, suggesting timescales ranging from two years to five years.

5.36 Comments made by interviewees about the timescales for the review often emphasised the significant amount of time that would be required to help people who may have little or no knowledge about, or experience of, the 2003 Act to understand the very complex issues that the review will be considering. For example, different individuals argued that:

- *'The timescales for the review need to be realistic.'* The early stages of the review will need to be spent in giving people with learning disabilities and autism information about the Mental Health Act so that they can give their views about possible changes in an informed and meaningful way later.
- *'The process for this review needs to be designed differently to make the process accessible to people.'* It will take time for Easy Read and other information materials to be developed and tested in an ongoing way during the review. It is important not to underestimate the time required to give people the support they will need.
- *'Consultations and events with people with learning disabilities are often too rushed.'* People often are not given sufficient time to think about issues and formulate their own responses to them. This results in participation feeling tokenistic.
- *'A five-year timescale would be realistic'* if the review includes a review of other related legislation in Scotland.

5.37 Given that there was a range of views expressed on this issue, the question of timescales was discussed at both workshops.

5.38 Among workshop participants, there was no clear consensus about what the timescales for the review should be. Views ranged from *'it should take as long as it takes, but there should be regular updates and communication about progress'* to *'it*

¹⁹ Scottish Government (2016) *Mental health in Scotland – a 10 year vision*. Consultation paper. Available at: https://consult.scotland.gov.uk/mental-health-unit/mental-health-in-scotland-a-10-year-vision/supporting_documents/mentalhealthstrategy.pdf. See Annex A, page 8.

should be completed within 18 months from April 2017.²⁰ Those who argued for shorter timescales were those in learning disability groups who wanted the review to be completed, and any new or amended legislation to be brought before the current Parliament (i.e. before May 2021).

5.39 The following is a summary of the range of comments made by workshop participants on the subject of the review timescale:

- Information will need to be developed and made available to people in a range of formats. The review should allow sufficient time at the start for developing and sharing this information.
- The use of face-to-face consultation (in small groups) is likely to work best for people with learning disabilities. This will have implications for the timescales of the review.
- The timescales for this review should be similar to those of the Millan Review (i.e. about two years for the review process itself).
- It is important that a timescale is set for the review and that this is adhered to, rather than allowing the process to go on indefinitely.
- A timescale of 18 months from April 2017 would effectively mean 12 months for fieldwork (evidence gathering and consultation) and 6 months for writing up the findings. There was a query about how realistic this was.
- However, a counter-argument was that different aspects of the fieldwork could be run in parallel to meet the 18-month deadline.

²⁰ This 18-month timescale is based on the timescale proposed during the debate on the Mental Health Bill of 'three years from the date of royal assent'.

6. Conclusions and recommendations

6.1 This scoping study was the first stage of a review of the Mental Health (Care and Treatment)(Scotland) Act 2003 as it concerns people with learning disabilities and autism.

6.2 The study sought to lay the foundations for the review by gathering views from selected key stakeholder groups about:

- What the scope of the review should be
- Who should be involved
- How the review should be conducted.

6.3 One key message from this work was that learning disability and autism are different, but related. On the one hand, the review must acknowledge the diversity in both conditions, but on the other, it must recognise that there is also significant comorbidity between the two, and between both sets of conditions and mental illness.

Scope

6.4 In general, those who participated in this study understood that the main aim of the review would be to answer the question: Should learning disability and autism continue to be covered by the 2003 Act – or not? Participants suggested a range of issues they wanted the review to look at – many of which would involve a detailed examination of how different aspects of the 2003 Act are working in practice for people with learning disabilities and autism. They also wanted the review to consider whether and how this current practice measures up to human rights standards which have developed since the law came into force.

6.5 However, this broad understanding of the purpose of the review was not shared by all participants in the study. In particular, representatives from People First argued that the review should start with the question of whether learning disability and autism should continue to be defined as ‘mental disorders’. Given the almost unanimous agreement among those who took part in this study that they should **not** be defined as ‘mental disorders’, the main aim of the review would therefore be to consider what kind of legislation is needed to support people with learning disabilities and autism to become empowered citizens.

6.6 Those who held this second view did not accept that the review should seek to answer questions about whether a legislative power is needed to make decisions for people who lack capacity, or to require people to accept treatment which they

disagree with, since they argued that such powers are not consistent with the UNCRPD.²¹

6.7 One possible way of reconciling these two divergent views would be to shift the initial focus of the review from whether learning disability and autism should be included in the definition of “mental disorder” in the 2003 Act to what sort of legal provision would best ensure that the human rights of people with learning disabilities and autism are fully respected. This would allow for the review to start from first principles in considering the best approach to take in relation to the care and support of people with learning disabilities and autism. Having explored this, it could then move on to considering whether the approaches identified would be best achieved by amending the 2003 Act or whether new legislation may be required.

6.8 Should this alternative approach be agreed by the Scottish Government, the questions for the review as proposed in paragraph 3.39 above might then be reframed as follows:

- what sort of legislative provision (if any) is needed to protect and enhance the human rights of people with learning disabilities and autism?
- What role does ‘diagnosis’ have in any (potential legislative) response?
- What is the best way to help people with learning disabilities or autism who break the law, or who are at risk of breaking the law?
- How can ‘supported decision-making’ be used in practice in the care and treatment of the wide range of people who have learning disabilities and autism?
- Under what circumstances, if any, might it be justified to detain a person with a learning disability or autism in hospital, or require them to accept medical treatment to which they have not consented? If such circumstances exist, what protections are needed?
- How can the law help people with learning disabilities and autism to have access to the right services to help them live independently?

6.9 Taking into consideration the answers to the above questions, two further questions would then be:

²¹ This reflects the position of the Committee on the Rights of Persons with Disabilities, in its General comment No 1 (2014) on Article 12 of the Convention. For a different view on what the Convention requires, see *Towards Compliance with CRPD Article 12 in Capacity and Incapacity Legislation across the UK – Three Jurisdictions Report: Essex Autonomy Project Position Paper 6 June 2016* - <http://autonomy.essex.ac.uk/uncrpd>.

- Are the principles set out in the 2003 Act relevant to learning disability and autism, or should the principles be updated or changed?
- How should the 2003 Act be amended and / or might new legislative provision be required?

6.10 The benefit of this type of approach is that it is consistent with the commitment made by the Scottish Government to have a review, and it does not assume any particular outcome. This type of focus is also consistent with the widely held view that this review should be holistic and consider not only provisions relating to people's care and treatment, but also provisions relating to guardianship and the protection of vulnerable adults.

A wider review?

6.11 It was not within the remit of this scoping study to consider whether there should be a wider review of all mental health and incapacity law, as this study was focused on the Ministerial commitment given in June 2015. However, it is striking how often the issue was raised. The Mental Welfare Commission is on record as saying that the entire legislative framework for non-consensual care requires a comprehensive review.²² Whether a wider review happens is a matter for the Scottish Government; however, the Government has now proposed a review of incapacity legislation in 2016-2018,²³ as well as the review in relation to learning disability and autism in the 2003 Act. We believe these two reviews need to be part of a coherent and joined up process, since any substantial change to one Act is bound to impact on the other.

Need for further research

6.12 In discussing their thoughts about the scope of the review, participants in this study identified several areas where evidence would need to be gathered to inform the review's deliberations. It was clear that participants wanted the review to obtain a clear understanding of how the 2003 Act is being applied to people with learning disabilities and autism. This finding affirms the suggestions made by the Millan Committee (as set out in paragraph 1.6 above).

6.13 Specifically, participants thought the review should examine:

- How the 2003 Act is being used for people with learning disabilities and autism

²² Response from the Mental Welfare Commission for Scotland to the Scottish Government consultation on Adults with Incapacity: http://www.mwcscot.org.uk/media/315711/sg_slc_awi_consultation_doc_216.pdf

²³ *Mental Health in Scotland – a 10 year vision*: <https://consult.scotland.gov.uk/mental-health-unit/mental-health-in-scotland-a-10-year-vision/>. See Annex A, priority 8 on page 8.

- The experiences of people with learning disabilities and autism in the criminal justice system
- The experiences of other jurisdictions.

6.14 Regarding the first point, research could draw on data held by MWC about people with learning disabilities and autism who have been subject to the 2003 Act. This includes (for Compulsory Treatment Orders (CTOs)) information taken from the applications and Tribunal decisions about why a CTO was thought to be necessary. This data could be supplemented by interviews with the people involved in a sample of cases to explore different perspectives on questions like: (i) Could compulsory measures have been avoided if other supports had been available? (ii) Did the use of compulsory measures benefit the person and if so, how? and (iii) What were the outcomes for the person?

6.15 Regarding the second point (in paragraph 6.13 above), similar research could also be carried out in relation to the relatively small number of people with learning disabilities and autism who have received mental health disposals in the criminal justice system. However, this would not address the concerns expressed by some participants about people with these conditions in the criminal justice system who are **not** given a mental health disposal. Research being carried out by the Equalities and Human Rights Commission²⁴ and groups like the SOLD Network²⁵ might shed light on the experiences of these individuals. It may also be possible to carry out a separate study to explore whether there are any significant differences between people with learning disabilities and autism who receive mental health disposals and those who are sent to prison. (MWC has carried out a similar study in relation to women offenders with mental health problems.²⁶)

6.16 The experiences of other jurisdictions (the third point in paragraph 6.13) could be identified through a literature review and evidence gathered from key informants. This work could be undertaken by a legal / academic institution.

6.17 Research on these three topics would provide a perspective on what is **currently** happening and, potentially, all of this work could be commissioned before the review

²⁴ The Equality and Human Rights Commission has recently awarded a research contract to explore the experiences of people with learning disabilities in the Scottish criminal justice system.

²⁵ SOLD = Supporting Offenders with Learning Disabilities. See <http://soldnetwork.org.uk/>. SOLD recently organised an event to consider the question of how to improve support for an accused person with a learning disability from arrest through to and including the court process.

²⁶ *Mental Health of Women Detained by the Criminal Courts*: http://www.mwscot.org.uk/media/190441/women_offenders_final_report.pdf

begins. This would allow the findings to be made available to the review at an early stage.

6.18 In relation to the question of what type of legislative provision (if any) is needed for people with learning disabilities and autism, the review will also need to consult widely, and this process will take time.

6.19 Related to this, a fourth area for research might involve a study similar to the VOICES project being conducted in Ireland (see Box 2 in Chapter 3). This would involve people with learning disabilities and autism working together in a structured way with health and social care professionals and law experts to explore what a human rights based response is in relation to issues of legal agency, consent to treatment, criminal responsibility, and the use of supported decision-making. This would be an ambitious project and would require a significant commitment of time. However, such a study would be particularly relevant if the Scottish Government chooses to carry out a wider review of capacity-related legislation in Scotland (not only the 2003 Act, but also the Adults with Incapacity Act and the Adult Support and Protection Act).

Who should be involved

6.20 There was general agreement about the individuals and groups that will need to be involved in the review. Chapter 4 has summarised this information and Annex 3 includes the names of specific organisations and groups that should be involved. During this study, representatives of several organisations offered help in organising consultation activities and supporting people with lived experience of learning disability or autism to be involved in the review.

6.21 There was also agreement that the review should consult widely and make every effort to obtain views from the wide range of people who may have a learning disability or autism, and their families and carers. There was concern that the review should not rely solely on the views of individuals and groups who have been campaigning for change.

Conduct of the review

6.22 Regarding the review group, a consensus appeared to emerge about the nature of the group.

6.23 There was general agreement that the review should have a single chairperson. (A suggestion of two chairpersons, one of whom would have lived experience of a learning disability, was not generally supported.) The chairperson will need to be independent (and seen to be so), credible, willing to listen to all points of view, clear-

thinking and able to make decisions. Knowledge of the topic would be an advantage, but was not thought to be a priority. Knowledge of, and a commitment to, human rights was seen to be particularly important.

6.24 There was general agreement that the chairperson should be supported by a small core group (6 to 8 members was suggested), with additional reference groups who could be consulted about specific issues.

6.25 There was no consensus about the timescales for the review. The Scottish Government has proposed a start date for the review 'before April 2017'. Some participants were keen to adhere to the suggested three-year timescale from the date of royal assent of the Mental Health (Scotland) Act 2015 – thus leaving just 18 months for the review. These individuals were concerned that the review should be completed and any changes to legislation (if required) set in motion before the end of the current parliamentary term.

6.26 However, given the general agreement that the review must consult widely, we believe a longer timescale will almost certainly be needed. Meaningful consultation with the wide range of individuals and groups who need to be involved in this review will take time and the design of the review process and timescales need to acknowledge this.

Conclusion

6.27 When we began this study we were concerned that, amongst those who had any view on the issue, there were two diametrically opposed positions. For many people with learning disabilities and autism, and some of the organisations who support them, the inclusion of learning disability in the 2003 Act was a mistake from the beginning, which needed to be corrected as soon as possible. For other organisations and many professionals concerned with the care and treatment of people with learning disabilities and autism, there was serious concern that changing the law would be hugely complicated, and potentially lead to worse outcomes for the small number of people who need to be detained in a hospital setting or given treatment for their own safety and wellbeing.

6.28 It was not our job to decide between those positions or to force consensus where it does not exist; rather our job was to explore how best this review should take forward its important work. As this report demonstrates, there is a good deal of consensus on some issues, but profound differences remain and cannot be ignored. We hope, however, that our study will help the review to negotiate these in a way which is inclusive, credible and visionary.

Annex 1: Survey responses

List of organisational respondents

Local authorities / NHS bodies / Health and Social Care Partnerships (11)

- Aberdeen City Council
- Clackmannanshire and Stirling Councils
- East Dunbartonshire LD / MH teams and relevant staff in HSCP
- East Renfrewshire Council
- Fife Health and Social Care Partnership
- Learning Disability Services across the three Health and Social Care Partnerships in North, South and East Ayrshire and Arran
- Kelvinbank Resource Centre staff group, East Dunbartonshire Council
- Learning Disability Division, NHSGCC
- NHS Lanarkshire, Occupational Therapy, Learning Disability
- North Lanarkshire Health and Social Care Partnership
- Renfrewshire Learning Disability Service Community Team

Professional / regulatory bodies (5)

- Care Inspectorate
- General Medical Council
- RCGP Scotland
- Social Work Scotland
- Social Work Scotland Learning Disability Sub Group

Third sector organisations (6)

- Autism Argyll
- Dunoon Autism Support Group
- ENABLE Scotland
- Grampian Opportunities
- Scottish Association for Mental Health
- Scottish Independent Advocacy Alliance

Learning disability or autism service user, advocacy or campaign groups (4)

- Autism Rights
- Ellon Resource Centre service users group, Aberdeenshire
- People First (x2), including national strategy group

Response rate to survey questions

Consultation question	Number of responses	% of 60 responses*
To what extent are the suggestions made by Millan still relevant to consider in the review?	51	85%
Are there any other issues you think the review should look at?	53	88%
Are there any issues that you think the review should NOT look at?	30	50%
Do you have any views about how the review should be governed or led? Please explain your answer.	43	72%
What are your thoughts about how the review should gather evidence and consult people?	43	72%
Which individuals / groups / organisations should be involved in the review?	45	75%
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.)?	42	70%
If you are aware of any examples of good practice for engaging with different groups which might provide lessons for the review, please describe them briefly here.	39	65%

* Comments made in the three Easy Read responses have not been included in the calculation of response rate as the questions in the Easy Read questionnaire were slightly different.

Annex 2: Interviewees and workshop participants

Interviewees

Representatives from the following organisations and groups were interviewed in June and July 2016 as part of stage 2 of the study.

- ARC Scotland
- Autism Rights
- British Psychological Society DCP-Scotland (Learning Disability Group)
- Down's Syndrome Scotland
- ENABLE Scotland
- Institute of Health and Wellbeing, Glasgow University
- Law Society of Scotland
- Learning Disability Alliance
- Learning Disability Nursing Forum
- Mental Health Tribunal for Scotland
- National Autistic Society, Scotland
- North Aberdeenshire Community Learning Disability Team
- PAMIS
- People First
- Royal College of Psychiatrists
- Scottish Government's Keys to Life Expert Group on Learning Disability
- Scottish Human Rights Commission
- Social Work Scotland (learning disability group)

Workshop participants

Workshops were held on 23 August 2016 (in Glasgow) and 16 September 2016 (in Edinburgh). Individuals from the following organisations and groups took part.

August workshop participants (autism)

- British Psychological Society
- Autism Argyll
- Autism Rights
- Grampian Opportunities
- Learning Disability Nursing Forum
- Mental Health Tribunal for Scotland
- Mental Welfare Commission for Scotland
- National Autistic Society, Scotland
- North Aberdeenshire Community Learning Disability Team
- Royal College of Psychiatrists
- Scottish Commission for Learning Disability
- Family carers and person with autistic spectrum condition

September workshop participants (learning disability)

- British Psychological Society
- Down's Syndrome Scotland
- ENABLE Scotland
- Learning Disability Alliance
- Learning Disability Nursing Forum
- Mental Health Tribunal for Scotland
- Mental Welfare Commission for Scotland
- North Aberdeenshire Community Learning Disability Team
- PAMIS
- People First (3 participants and 2 supporters)
- Royal College of Psychiatrists
- Scottish Commission for Learning Disability
- Scottish Government's Keys to Life Expert Group on Learning Disability (4 participants)
- Social Work Scotland (Learning Disability forum)

Annex 3: Organisations that should be involved in the review

Participants in the scoping study suggested that the following organisations should be involved in the review. Note that many of these suggestions were made by one or two respondents only.

Statutory bodies

- Local authorities
- Mental Health Tribunal for Scotland
- The Mental Welfare Commission for Scotland
- NHS Boards
- Police Scotland
- Scottish Human Rights Commission

National third sector organisations

- The Alliance
- ARC Scotland
- Autism Initiatives
- Autism Network Scotland
- Autism Resource Centre
- Autism Rights (including the Highland group)
- British Institute for Learning Disabilities
- ENABLE Scotland
- Inclusion Scotland.
- Independent Living in Scotland (ILIS)
- Institute for Research and Innovation in Social Services (IRISS)
- Learning Disability Alliance Scotland (LDAS)
- National Autistic Society and National Autistic Society Scotland
- National Development Trust for Inclusion
- National Involvement Network
- Outside the Box
- People First / People First (Scotland)
- Psychiatric Rights Scotland
- Scottish Association for Mental Health
- Scottish Autism

- Scottish Commission for Learning Disability
- Scottish Council of Voluntary Organisations
- Scottish Learning Disabilities Observatory
- Supporting Offenders with Learning Disability
- Treating Autism
- Values in Action Scotland (VIAS)
- Voluntary Health Scotland

Local third sector organisations

- Glasgow Centre for Inclusive Living (GCIL)
- Glasgow Disability Alliance (GDA)
- Lothian Centre for Inclusive Living (LCIL)
- Grampian organisations: Advocacy Aberdeen / Advocacy North East; The Arches (Banff); Comraich (Inverurie); Learning Disability Group of Aberdeen and Aberdeenshire; Grampian Opportunities; Mental Health Aberdeen; Pillar Kincardine; Network of Wellbeing (Huntly)
- East Ayrshire organisations: VIP's; UCAN

Professional / regulatory groups / bodies

- British Psychological Society-DCP Scotland Branch
- Learning Disability Senior Nurse Group
- National Learning Disability Professional Senate
- Royal College of General Practitioners
- Royal College of Psychiatrists (including the Learning Disability Faculty)
- Scottish Association of Social Workers
- Social Work Scotland

Academic / research bodies

- Critical Psychiatry Network
- ESPA Research

Annex 4: Suggested methods for gathering evidence and consulting people

Participants put forward a range of specific suggestions for how the review should gather evidence and consult people. These included:

- Face-to-face methods including consultation events and workshops, conferences and road shows – these were all seen as useful for allowing meaningful dialogue, exploring views and experiences, and engaging with those with learning disabilities in particular
- Engagement techniques such as World Café discussions, wish trees, post-it notes, idea walls, etc.
- Interactive methods and activities using theatre, video, or drawing
- Focus groups / small discussion groups – with the caveat that this could be a resource-intensive method with success depending on adequate input and preparation from skilled facilitators
- Visits to services, including hospitals and advocacy services
- Surveys – with specific calls for these to be simple and widely circulated
- Online methods including: online surveys – seen as particularly useful in engaging those with autism, and getting input from professional groups – and social media
- Impact statements, (recorded) oral evidence sessions and case studies
- Submission of written evidence
- Literature reviews, with the aim of capturing information about alternative service models and legislation in other jurisdictions.

Practical issues

Participants were asked for their views on any practical issues which would need to be addressed to ensure that the review was carried out successfully.

Comments addressed the following issues: information and communication requirements; 'environmental' factors; location and timing of meetings and events; format of events; support needs; expenses. Key messages – explicitly or implicitly stated – were about the importance of: (i) accessibility, (ii) sensitivity to the needs of different groups

and individuals, and (iii) actively facilitating the inclusion of all those who wished to contribute to the review whether they be individuals with a learning disability or autism, or their families or carers. Respondents emphasised the need for the review to adopt a flexible, 'person-centred' approach allowing individuals to engage in the process in a range of ways.

Involving those with learning disabilities and autism, their families and carers and / or groups representing their interests in the running of the review and the planning of review activities was seen as one way of ensuring that the needs of potential participants were catered for.

Information and communication requirements

Accommodating the very varied information and communication needs of potential participants was seen as crucial to the success and legitimacy of the review. At a general level participants stressed the need for: (i) information to be available in appropriate formats for those with varying levels of understanding, and (ii) support to be available for those with intellectual and communication difficulties to help them understand issues and convey their views. More specifically, participants commented that the review would need to incorporate or accommodate:

- Easy Read, user-friendly written materials (for all participants, as well as those with learning disabilities – some argued that material should be 'easy read' as standard, with more detailed information available as 'add-ons')
- The development of clear questions and the use of appropriate methods for explaining abstract concepts
- Use of communication aids such as Talking Mats, Alternative Augmentative Communication systems, emotion cards, DisDAT (Disability Distress Assessment Tool)
- The use of visual aids and media such as story boards, video and theatre.

Participants called for the involvement of appropriate organisations (e.g. SCLD) and professionals (e.g. speech and language therapists) in developing consultation formats and materials.

Location and timing of meetings and events

The location and timing of events were significant issues for respondents, particularly those responding as family members or carers of those with a learning disability or autism. There were calls for events to be held across the country, in local communities and in locations with good transport links in order for them to be easily accessible to a

wide range of people. The time, cost, inconvenience and challenges of travelling to (unfamiliar) locations were all seen as potential barriers to participation. Further, people thought that holding events in local areas could be helpful in demonstrating a commitment to hearing the views of all sectors.

With regard to timing, respondents highlighted the need for events to be held at a range of times – and for adequate notice to be given – to fit in with different work and caring commitments, and to ensure the process was not biased towards those attending in a professional capacity. Offering a range of timings was also seen as important for those with learning disabilities and autism whose concentration levels may vary through the day.

Venues and ‘environmental’ factors

Participants also had clear views on the types of venues which might be used for meetings or events, with two main points made. Firstly, they stressed the benefits of holding meetings and events in informal settings where people would feel safe, secure and at ease; holding events in familiar venues and collaborating with local groups in running events was also seen as important by some in this respect. Secondly, they highlighted that venues should be accessible for those with physical disabilities and, crucially, should offer low sensory environments and separate spaces for those who may need time away from the main event.

Format of events

Participants raised a number of practical issues related to the format of events and meetings.

On duration of events, there were two views: (i) that events needed to incorporate sufficient time for people of all abilities to consider and understand issues, and formulate their response, and to receive assistance with this if required; and (ii) that events needed to be short and focused. It was also suggested that people should be given advance notice of what to expect at events and given preparation time beforehand.

The importance of skilled facilitation provided by those with experience of working with the target groups was also noted.

The point was made that participation in the review might be encouraged by using existing events or group sessions to engage with people, or including a social element such as lunch / refreshments / bingo / music.

Support needs

Participants stressed the importance of providing support to individuals with learning disabilities and autism (and others) to allow them to take part fully in the review, with most discussing this issue in the context of face-to-face meetings and events. Support was needed to help people understand and consider concepts and ideas (in preparation for, and at events) and to help them develop and contribute their own views. For some this meant ensuring that individuals could attend events with family members or carers; others mentioned the need for input from skilled facilitators, speech and language therapists and psychologists.

Some people commented that those affected were best placed to know their support needs – the involvement of local groups and organisations in organising and facilitating events was seen as helpful in this respect.

Expenses

Some participants pointed out the financial implications of attending events, and suggested that the expenses should be provided to cover costs incurred in attending events (travel and subsistence, care arrangements). Some also noted that family members were often self-employed or worked in contract jobs in the care sector and suggested the review should compensate people for lost earnings. There was concern that without such financial support, the review would not hear from all sectors.

Annex 5: Examples of good practice

The discussion paper and survey issued at the beginning of the scoping exercise asked people to share any examples of good practice in engaging with different groups so that this might inform the conduct of the proposed review:

Participants offered a variety of examples of good practice, referring to: (i) engagement activities they were aware of or had been involved in as organisers or participants or (ii) toolkits or resources developed for use with particular groups. This information has been collated below. In most cases, the examples were mentioned by one respondent only, and included only limited information.

Participants' more general comments on approaches and methods they thought could be used in carrying out the review have been discussed in Annex 4.

Engagement exercises and events

- 'Partnership in Practice' exercise in Dundee carried out as part of local response to *'The Same as You?'*
- Review of *'The Same as You?'* consultation events
- Scottish Dementia Working Group's work advising the Scottish Government on dementia issues
- Focus groups involving people with mild to moderate learning disabilities in Fife carried out in order to find out their views on themes within the Keys to Life Strategy – an evaluation of this engagement exercise had been carried out
- 'What Matters to You' event – a one day 'conversation' with people with learning disabilities organised by integrated disability service and day supports for people with learning disabilities in Renfrewshire which had involved gathering views from 64 people in various settings and circumstances
- The Millan Review – especially with regard to using a range of approaches, holding meetings and events in a range of locations
- Facilitated discussion group for in-patients with learning disabilities at a local hospital.

Toolkits and other resources

- Ketso – a kit for running interactive community engagement activities
- Royal College of GP's ASD toolkit
- ENABLE's facilitators' pack for guiding discussion
- 'Social stories' – a technique for engaging those with autism

- Scottish Community Development Centre's National Standards for Community Engagement
- ARC Scotland / National Involvement Network's Charter for Involvement
- Learningdisability.co.uk
- Publications produced by MWC
- Mencap's 'Wecan2' research on engagement
- 2011 research carried out by the National Council for Voluntary Organisations (NCVO) / Institute for Volunteering

Other participants referred to successful activities that they were aware of or had been involved in which had used approaches such as:

- Evening events for people with autism – these were well attended and appeared to be more convenient and less stressful than day-time activities
- Using existing (already scheduled / planned) events to make contact with relevant people
- Consultations which allowed participants to consider issues prior to attendance at events
- Online communication / social media / email / virtual meetings.

It was also suggested that there would be examples of good practice in engagement and inclusion in local autism and learning disability strategies.

Organisational approaches

- 'Voices for Change' model used by Grampian Opportunities – this had recently been used with hard to reach groups in relation to health and social care integration and showed the value of meeting people in their own environment
- Facilitation approach used by Outside the Box including on its recent 'Permission to dream' project
- The VIP Service User Group's use of creative activities led by community groups to engage and stimulate discussion
- People First's approach based on residential events at which people can develop understanding and opinions and prepare views prior to presenting to others – as used in giving evidence to the MacManus Review and the Health and Sport Committee of the Scottish Parliament
- Scottish Learning Disabilities Observatory's use of play acting by people with learning disabilities as a way of stimulating discussion.



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St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-78652-710-3 (web only)

Published by The Scottish Government, December 2016

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS260876 (12/16)

W W W . G O V . S C O T