

Response to LD and autism in MHA consultation

1. What Scotland needs to do

We generally support the approach set out in section 1.2 of the Final Consultation document. We agree that we need to ensure that the law complies with the European Convention on Human Rights, and that Scotland should live up to the commitment to implement the UN Convention on the Rights of Persons with Disabilities. How this can be done is not simple, and it is important to proceed in a way which is conceptually clear, starts from where we currently are, and develops practical solutions.

We welcome the fact that the review has sought to do this. In some areas the proposals for legal and service change are extremely radical, with significant risks if not properly thought through and justified. We agree that there is much that needs to be improved about support for people with learning disability and autism, but it is an over-simplification to suggest that the current law and services universally reflect a paternalistic medical model.

We welcome much of the direction of travel set out at 1.3, but with some significant caveats:

- We do not agree that 'it should not be possible to challenge the legal capacity of autistic people or people with learning disability'.
- We agree that the law and services should change to stop people with learning disability and autism being kept in hospital for far too long. However, in talking about 'a shift away from compulsory treatment in hospitals that emphasise medical treatment' it is important to recognise that the number of people with autism and learning disability who are detained in hospital is a small proportion of the much larger number of people with learning disability or autism who are currently supported in the community. A shift to a new model such as 'secure support centres' would need very careful design, justification and development, if it is to avoid recreating institutional care in another setting.
- We are interested in exploring what new powers might be appropriate for the Mental Welfare Commission, although we see challenges in the very sweeping powers which are suggested.
- We think the changes to the status of mental disorder in criminal law require more detailed thought
- Given that it is acknowledged that compulsory treatment and detention may be necessary for some people with autism and learning disability, at least for some time, we are not persuaded that they should be removed from the Mental Health Act and have this authorised by another piece of legislation. In general, we feel the more promising way forward is to bring legislation together into a unified framework (covering mental health, incapacity and protection), rather than create different laws based on particular conditions or diagnoses.

How could we make this better?

We agree with the principle that adults with learning disability or autism would benefit from augmented community supports. Additional training and investment in local services for adults with autism in particular, might reduce the potential for them receiving care in the wrong settings and from services which are not equipped to deliver the right care.

Recognition and added endorsement from a government level on the benefits of SDS and the integration of health and social care services is also required.

We would like to see the impact of the potential financial gains made from integration being developed into additional community supports for adults with autism and LD.

We discuss other aspects in more detail in our response to later sections of the document.

2. How we understand autism and learning disability

We agree that autism and learning disability should be understood as disabilities. We would say the same for other conditions encompassed by the definition of 'mental disorder' in the 2003 Act, including mental illness, dementia, brain injury and personality disorder. Defining learning disability and autism as disabilities does not answer the question of whether and how they should be included in the Mental Health Act.

The fundamental reason the various conditions classed as 'mental disorders' in the Act are grouped together is that they are all capable of impairing the ability of the person to make an autonomous decision about their care and treatment. In our view, that is a justifiable basis for having legislation directed at this broad class, although there are reasonable questions to be asked about why we treat this group differently from other people whose impairment may be more transient or self-inflicted.

The distinction the review makes between an impairment and a disability is potentially helpful in thinking about how mental health law should operate. There should be a duty on society to overcome environmental barriers which hinder the participation of a disabled person in society, and failure to provide appropriate support for decision making is one such environmental barrier. Ultimately, however, we believe the law needs to provide a solution where, even with the maximum practical support, a person is unable to make an autonomous decision about their care.

We support the development of a human rights culture in services. The proposals later in the document for restrictions of liberty to be based on human rights assessments are radical and challenging, and can only succeed if there is a shared understanding of what human rights are, and how different human rights can be balanced to reach a defensible conclusion.

It's also important to recognise that the notion of human rights being central to care is not new. Much of the 2003 Act already reflects a human rights based approach, as do the Health and Social Care Standards, and legislation such as Self Directed

Support – even although implementation is often patchy. Human rights based practice is a feature of the work of many practitioners in mental health, and has been supported by initiatives such as the Scottish National Action Plan and various initiatives by the Commission.

In relation to risk, we feel the statements on page 17 about a risk averse culture in learning disability services are overly sweeping, and do not reflect good practice which already exists in many services around positive risk management.

In relation to codes of ethics, health and care professionals already have such codes, although we agree that it would be helpful to develop further a shared understanding across services of the obligations to respect the rights of people they support.

In respect of legal capacity, we agree that there should be stronger rights to support for decision making, discussed in the next section. We appreciate the position of the UN committee on the Rights of Persons with Disabilities, but we do not agree that ‘it should no longer be possible to challenge the legal capacity of autistic people or people with learning disability’.

In our view, some people have such significant impairments that, even with support, they are not able to make an autonomous decision. When that happens, there needs to be an appropriate framework for others to make a decision for the adult, with safeguards against abuse. This could be justified by the UN Committee’s concept of ‘best interpretation of will and preference’, although we feel that this approach may be necessary in more situations than the Committee would envisage. Our approach is broadly consistent with that of the Essex Autonomy Project Three Jurisdictions report, which we see the review generally endorses.

Any change to the criteria for substitute decision making should apply universally, rather than be restricted to autism and learning disability.

How could we make this better?

The suggested right to support for decision making would need to specify who owes a duty to secure such support.

3. Support for decision making

3.1 We accept that adults with autism or learning disability should be supported to exercise their legal capacity to their full potential, but we would qualify this by acknowledging that for some, they are unable to do so completely as a result of cognitive impairment. As the law currently operates there is an opportunity and arguably a requirement to provide support to maximise this capacity. There is a need to strengthen this, but it could be done by improvements to the current legal framework, and this should apply to all, not just to learning disability and autism.

The suggestion that this could be done by requiring ‘special regard’ to be had to a person’s rights, will and preferences is an interesting and potentially useful one, but it would be important to decide and explain how this would differ from the current principle of the Act that professionals must have regard to the person’s present and past wishes and feelings. In other words, what does ‘special’ mean?

We agree that Advance Statements, as they appear in the 2003 Act, are narrowly focused on medical treatment during compulsion, and it is unhelpful that they are separate from other forms of anticipatory care planning.

We welcome the idea of a statement of rights, will and preferences as a development from Advance Statements, although we feel this could be applied to everyone with a mental health condition. We also agree that the justification for not following a statement of rights, will and preference could be based on a human rights assessment, including an assessment of proportionality.

However, in saying that professionals should ‘act to put each person’s will and preferences into effect’, it’s important to distinguish between things that the person wants to happen and things they don’t want to happen. No-one has an unfettered right to demand that the NHS or other public services provide them with things that they want or would benefit from.

The idea that people could take a decision not to respect their statement of will and preference to the Tribunal is an interesting one, but may require some threshold to be set, to avoid minor differences in how care is delivered being taken to a judicial forum.

3.2 We welcome a strengthening of the role of advocacy, but have some concerns about over-emphasising this at the expense of other forms of support for decision making, for example circles of support.

We do not believe a need for support in decision making should be the sole basis for having the right to an advocate. Some people are perfectly able to decide what they want, but struggle to be heard, and need advocacy to support them in doing this.

Where a decision is taken on a ‘best interpretation of will and preference’, we are not convinced an advocate should be the final arbiter of that interpretation. This is not the role of an advocate, even a non-instructed advocate – judicial bodies and professionals need to take and justify those decisions.

3.3 A formal role for a ‘decision supporter’ may be helpful, but may need to be combined with some pruning of the large number of people who already can be involved in proceedings under the Act, including a legal representative, a curator ad litem, an advocate, a named person and a listed initiator. This wealth of representation risks the views of the adult being lost.

3.4 In relation to carers, much of what is in 3.4 reflects current good practice – albeit it is not always implemented. Further clarification would be helpful on what changes are being proposed to the law.

3.5 We agree that standards for accessible information may be helpful. We are not sure whether we are better positioned than other organisations to set those standards, but would be happy to consider this.

3.6 We agree with the suggestion that professionals should be under a duty to show that they have taken reasonable steps to support a person's own decision making about care and treatment. Suggestions that the Tribunal should separately consider and authorise each form of medical treatment including all psychological interventions might be unworkable as the boundaries as to what constitutes a psychological intervention are not always clear. Treatment plans are often better understood in totality rather than as their constituent parts, and in some situations a complex series of separate authorisations risks delaying appropriate treatment.

We noted that the section on psychological interventions seemed quite negative in tone about these treatments and wondered about the evidence around this, and what interventions 'which could cause serious harm' were being considered. We agree that there should be stronger safeguards for restraint and seclusion, but it is not clear if the review sees these as psychological interventions. It may be necessary to specify more narrowly what specific kinds of psychological intervention may require authorisation.

We also assume the review is talking about psychological interventions given without consent, although it does not say so.

There appears to be a circularity, in that psychological interventions can only be given 'where there was no other possible way for the person to receive the benefit', and the same test is applied to the use of psychotropic medication in 3.7. These will sometimes be alternatives, and ultimately one or other will need to be chosen.

3.7 We support efforts to reduce the use of psychotropic medication to manage the behaviour of people with learning disability or autism (see the recommendations in our recent themed visit report to autistic people with complex needs), and agree the suggestions made in 'What we think Scotland needs to do'. However we do believe that there are occasions where an antipsychotic medication might be helpful for behavioural disturbance in learning disability or autism.

The proposals for law reform do not distinguish between psychotropic medication when it is used to manage behaviour and when it is used to treat a mental illness. This is important as the prevalence of mental illness for people with learning disability is significantly higher than in the general community. In general, we'd prefer that additional safeguards apply to all groups, rather than carve out a particular regime for learning disability and autism.

It will also be important to address how far the proposals would require changes to the Adults with Incapacity Act, since that can be used to authorise psychotropic medication.

Many of the recommendations (such as regular reviews, not prescribing without seeking to understand the cause of symptoms) would already be good practice, and should be underpinned by the protections in Part 16 of the Act, including the

Designated Medical Practitioner system operated by the Commission. We're not sure how it is intended that this might change, and would be happy to discuss the detail. We'd also be happy to explore how we could build on our current data systems to monitor prescribing for this group.

3.8 The review proposes the establishment of safe places and secure centres. We agree that the response to people in crisis needs improving, but we are unclear what these would offer and who would operate them. We should not lose some of the benefits of a hospital admission, for example assessments of physical health care, mental health assessment and a holistic approach to crisis. Often in crisis it is difficult to ascertain the source of an individual's distress and this could be as a result of a mental disorder or an underlying physical health care issue causing pain. We would want to ensure that any safe centre potentially run by social care staff would be able to highlight such issues, and respond accordingly.

Similarly, we would want to understand more about how Secure Support Centres would differ from hospital – there are many practical issues about funding, through flow, and how they would manage situations of dual diagnosis.

Our experience of secure centres for young people is that they are scarce, expensive, difficult to access given restrictive criteria and are not designed to manage mental health care.

We have reservations on how an environment could accommodate both adults with a LD and adults with autism when they have different needs. A current criticism of hospital settings is that the management of adults with autism within learning disability specialist services is often not appropriate and highlights how the needs of the two groups may be incompatible.

How could these ideas be made better?

We would welcome opportunities for people to remain within their own homes at times of crisis and avoid the need for alternative environments. This would require an augmentation of community provision at crisis points, and would require significant investment in social care provision, for example supported living with a range of multi-disciplinary supports.

Building of safe and secure centres would require significant investment, especially sensory specific environments, and money could be put into community services.

Significant investment maybe required in relation to advocacy services and work undertaken with the Scottish Independent Advocacy Alliance.

4. Support, care and treatment

4.1 We agree that current rights (e.g. ss25-26 of the MHA) have not proved adequate to ensure that people with mental disorders, including autism and learning

disability, have access to appropriate support and care in the community. Stronger duties, which could be enforced by the individual or those who support them, would be welcome, if they can be formulated in a way which is clear, fair, and effective. In general, though, any rights framework needs to be supported by an infrastructure of services which needs to be developed.

4.2 We're not sure which services currently reject people from support because they have a learning disability, and agree this should not happen – indeed we suspect this would breach the Equality Act. We suspect it is more common that services simply do not try hard enough to ensure they are accessible to people with learning disabilities, and we agree that more should be done to overcome this, including around access to primary care, and ensuring that health and care staff have the right skills and knowledge to provide support to people with learning disabilities.

4.3 Similarly, we agree that health services for people with autism should improve. A national autism service may help, but we would want to see greater clarity on its role and governance. There is already a National Autism Implementation Team, and it is important that local services grow and develop local responses. We believe that services describing themselves as specialist should have this verified by performance and quality control – see our MN investigation.

4.4 We agree that a human rights assessment should include gender issues (alongside any other protected characteristics). We'd be interested to discuss further what improvements may be needed to ensure that mental health detention considers the rights of the parent and child. We note in passing that there appear to significant numbers of autistic people who are transgender, and the needs of this group may require particular consideration.

4.5 We agree that any issues affecting children with learning disabilities or autism should be considered in the context of planned legislation to implement the UN Convention on the Rights of the Child, including the interaction with the UNCRPD.

4.6 In discussing offenders, it would be important to distinguish between services which are delivered as part of a criminal sentence, and services delivered to a person who happens to have a criminal record. In the latter case, we agree that they should receive services of the same standard. In the former, there are other considerations, which we discuss later.

4.7 We discuss these proposals in responding to other parts of the document. However, in refining them, it will be important to clarify the ways in which these new responsibilities differ from existing duties on public bodies under the Equality Act.

How could these ideas be made better?

Investment in an infrastructure which offers choice of how a service is provided.

SDS is not mentioned in the report – a direct payment puts the adult at the heart of arranging care and support which meets their individual needs and would offer a more realistic rights based option.

With regard to providing support we would argue for a wider dissemination of the NES NHS Education autism training framework.

We also feel that knowledge and training should be highlighted when services for autism in particular are being commissioned.

5 Where support, care and treatment happens

5.1 A right to independent living is potentially helpful, but it would be important to clarify who owes the duty to ensure that it happens, and to define independent living, in a way which allows people flexibility in the choices they make about where they live.

5.2 See comments above on safe places. We support the development of new models of crisis response but, before a duty is set out in law, it would be important to have an evidence based model. The suggestion that ‘Professionals would have to detain a person if they thought the person was leaving the safe place to commit suicide’ raises a large number of issues, including what they would then do, what restrictions they could impose to prevent a person harming themselves in the safe place, and how to distinguish a concern about suicide from other risky behaviour.

5.3 As above, we do not believe that ‘the end of detention and compulsory support, care and treatment in hospitals’ is a realistic goal in the foreseeable future. Much more work would need to be done to clarify how ‘secure support centres’ would be safer, offer better treatment and respect human rights better than hospital, for the small number who require a compulsory intervention. This should be based on the development and evaluation of new services, not purely driven by a legal redefinition. We are concerned that this could involve a significant use of resource and policy capacity for what may be a lesser problem than the injustice of the current differential access to care.

5.4 We agree that any healthcare environment which may need to provide a service to a person with a learning disability or autism should be able to identify any particular needs arising from this, and make the necessary adjustments to meet those needs.

How could these ideas be made better?

Commitment to building local tailored community resources which could offer this kind of alternative response to a range of people.

6 How professionals make decisions

We agree that ending mental health detention is not a realistic goal, although it is important to state that such detention should not solely be 'on the basis of disability' (and isn't at the moment).

6.1 We believe the notion of a human rights assessment, allied to the development of 'statements of rights, will and preference', and the notion of 'special regard' for those will and preferences is a promising approach, albeit it requires a great deal of work.

In particular, the notion of 'proportionality' is a complex one to apply in individual cases, and if there is frequent recourse to tribunals to determine what it means, there is a risk of considerable confusion and potential under-treatment until there is a better shared understanding. This could take several years. Similarly, it will be important to be clear on what 'other limits to liberty' are in scope. Many of these would currently be considered under the Adults with Incapacity Act, not the MHA.

There are significant implications for training and resourcing to deliver the additional responsibilities of MHOs, and fitting these responsibilities with the current workload – which the current workforce struggle to meet.

6.2 We strongly agree that some people with learning disability or autism are hugely disadvantaged by the current system, although we're not sure it is correct to say that current services are not 'usually' able to meet the mental health needs of the generality of people with autism or learning disability.

Making the police power to remove 'disability neutral' sounds promising, but it would be necessary to work through who the police could then detain, and where they could be taken to, if it is not to be assessed for their need for treatment.

In relation to the proposed new criteria for compulsory intervention, we believe further work is needed on these:

- Mental disorder vs disability: the consultation cites the narrowing of the definition of mental disorder in the English Act, apparently with approval. It isn't evident to us that this has succeeded in reducing inappropriate hospitalisation of people with learning disability. More generally, we're not sure who is being detained now who might not be under this new definition
- Medical treatment vs support, care and treatment: Again, we're not sure how much practical difference this would make, other than potentially to broaden the scope of possible use of the Act. That may be justifiable if it increases safeguards for people who might otherwise be treated under the AWI Act
- Risk – we're not persuaded that this should be removed, and fear it may widen the scope of compulsion rather than narrow it
- SIDMA – we agree this should be looked at, but we're not sure what the new test would be, if it isn't a capacity test (following full support)

- Necessity – we can see merit in the proposed changes, although the key issue is probably how far the tribunal can insist on alternative provision from that which services are currently offering.

6.3 The shift of responsibility for care from Responsible Medical Officers to the Chief Social Work Officer has major implications, and we're not persuaded that the case has been made for such a fundamental shift. CSWOs often have limited direct knowledge or practice of mental health legislation. In relation to their responsibilities under AWI, these are typically delegated to frontline social workers. Even if they are better placed than a clinician to take the lead on someone's compulsory care, this approach risks diluting the personal accountability of the RMO. It may leave frontline staff in a vulnerable position when having to account for any lack of intervention.

6.4 We are not persuaded that there should not be a responsible clinician in the new model. If there is still to be some form of intervention which goes beyond what is permissible under the AWI Act, it is likely to involve some form of medical treatment – indeed ECHR may require this. If so, someone with appropriate expertise needs to be responsible for it.

7 How decisions are monitored

7.1 We agree with these suggestions.

7.2 The Commission is interested in exploring how its role might be expanded, although any expansion should be across the board, not confined to learning disability and autism.

We support the idea that the Commission might set human rights standards, as an extension of our current duties to promote best practice and provide advice and guidance on the use of legislation and the rights of people with mental disorders. We would not see ourselves being responsible for setting clinical standards, in the way that NICE or SIGN do.

We are less sure that we should become an inspection body with the powers to inspect, grade and potentially close services. This overlaps with the roles of HIS and the Care Inspectorate. It would require substantial changes to our staffing, funding and operating model, and risks diluting our focus on the individual patient, and our generally constructive relationship with services we visit. In particular, we are not currently set up to oversee issues of organisational culture, which often lie behind inadequate services.

We are aware that the Scottish Government is establishing a Quality and Safety Board for mental health services, which may allow these issues to be more fully thought through.

We are interested in the suggestion that we should have stronger powers of individual intervention, although this will require some boundaries to be set. We should not be seen as replacing either the normal mechanisms for local complaints, or the role of the tribunal. (At the moment, we have a power to discharge patients,

but generally do not exercise it, on the basis that the tribunal is better placed than us to do so.)

Of course, any significant expansion of the Commission's role would require to be full resourced.

7.3 We are generally supportive of the suggestions regarding the tribunal, and we agree that it is time to look at them having stronger powers than the current system (e.g. recorded matters) allows. That said, deciding when the tribunal should be able to order that local services must be provided or retained, if services say they are unwilling or unable to do so, will require considerable work.

The consultation does not address the role of proxy decision makers such as welfare attorneys and guardians. It will be important to set out how far they can authorise any limitations on the liberty of the disabled adult.

7.4 The suggested role for 'second opinion professionals' could be an expansion of the Commission's current role in respect of Designated Medical Practitioners. It would be necessary to consider operational issues, including how often such an opinion could be sought.

7.5 Bringing the CRPD directly into Scots law is potentially a difficult task, but could draw learning from the current plans to incorporate the UN Convention on the Rights of the Child. The Equality and Human Rights Commission has very limited resources in Scotland, so we're not sure how practical it would be for them to undertake 'an ongoing review process' of the MWC and tribunal. Some model of self-assessment validated by the EHRC may be more practical.

8 and 9 Offenders

We support the development of intermediaries, although it will be important to work through how this would sit with the appropriate adult scheme, which is only now being placed on a statutory footing.

The review discusses the issue of people who cannot participate in a criminal trial, but does not consider the separate case of the 'insanity defence' – i.e. the person's mental disability was so severe that they could not be said to have formed any criminal intent. In such cases, it is wrong to suggest that the 'punishment' should be measured against the punishment of a non-disabled person, since a person should not be punished for something they could not understand was wrong.

This is also the approach in relation to mental health disposals in the CPSA. It is fundamental to the forensic mental health system that the individual is a patient, not a prisoner, so the duration of 'punishment' is irrelevant. There has been a long journey to change the ethos of establishments such as the State Hospital to make clear that they are not 'prisons for the insane', and this should not be lost.

We agree that disability could be a mitigating factor. Indeed we think it is now – but the detail of this could be worked out by the Scottish Sentencing Council, which we understand wishes to consider sentencing for people affected by mental disorder.

More broadly, the current approach reflects an assumption that most criminal justice sentences are not well-suited to people with learning disabilities; so the best approach is to divert the person out of the criminal justice system and into appropriate care and support. That may seem to be discriminatory, but it may still be a better route to go down than hoping that prisons and community sentences can adequately accommodate people with learning disability or autism.

The review states that those who require to be placed in detention following a court appearance should be placed in a community setting, a rehabilitation centre or a specialist prison.

We are not convinced that a specialist centre or prison would be the answer. This could potentially mean centres located at a distance for some adults who would be away from family and other supports. It is suggested that they be led by social care staff supported by health care staff and could provide treatment. Clarification is required around the role and type of staff and the definition of treatment in this context. Would there be a difference in an adult's support and treatment between a social care staffed rehabilitation centre and an adapted prison which will presumably be staffed by prison officers?

Where the review suggests admission to hospital in this section- page 131- does this mean for physical ill health or for co –existing mental illness?

In relation to prisons, we note the huge problems of overcrowding and inadequate care in the current prison system. That may mean that ensuring people with learning disabilities or autism do not go to prison needs to be a priority in the short to medium term.

Could these ideas be made better?

We would suggest looking at existing provision and how this could be better equipped and resourced in terms of staffing and therapeutic interventions. We agree that where an adult with learning disability or autism ends up in a prison setting adjustments should be made.

Notwithstanding all we say above, we agree that there can be an injustice if people are subject to a mental health disposal for much longer than they may be sentenced for a criminal offence. Options to address this might be to provide that any order should be transferred to a civil order after a notional sentence duration, but only if the civil criteria are met, or making the criteria for continuing a CPSA mental health disposal the same as a civil order (i.e. include a SIDMA or similar test, and allow access to recorded matters, or any replacement).

10 What this means for the law

We have no objection in principle to a law setting out stronger positive duties to provide appropriate support to autistic people or people with learning disabilities, although in policy terms it would be important to explain why these groups deserve stronger rights than other people with disabilities.

In relation to compulsory powers, we are not currently persuaded that it would be right to separate out two forms of mental disability and create entirely separate legislation for them. Nor are we currently persuaded that autism and learning disability should be removed from the definition of mental disorder. However, we recognise that in many ways the 2003 Act has been framed primarily around the needs of people with mental illness, and that there are strong arguments either way.

In New Zealand, people with learning disability used to be subject to the same laws that governed the care of other people with mental health disorders. In 1992 learning disability was taken out of the Act, and anecdotally this led to a situation where people with learning disability were not afforded the same protections with regards disposals to hospitals as people with other forms of mental health disorders. New Zealand had to pass another law in 2004 to try to close this gap. Anecdotally psychiatrists in New Zealand had to suggest that their LD patients had other forms of illness that might account for behavioural difficulties, regulation of mood and impulse, etc., that led to difficulties in society.

We do not suggest that the proposals would result in exactly the same issues as in NZ as the review is sensitive to this. However, the underlying situation would be the same and we are concerned that similar problems may arise.

We note the comment in the Review that ‘it would be confusing and arbitrary in practice to have autistic people and people with learning disability subject to one law when diagnosed with mental illness or learning disability, and another when not diagnosed with these conditions.’

That suggests that autistic people or people with learning disability who *do* have a mental illness or personality disorder would not be subject to the Mental Health Act but to this new law – presumably even where it is the presenting mental illness which is the main reason why compulsion may be needed. This feels potentially confusing, particularly where a diagnosis of a co-morbid condition may be uncertain, and it would also mean that the new law would have to cover all the ground covered by the Mental Health Act.

On balance, then, we believe the best way forward in modernising mental health law is to look at how the Act measures up to modern human rights standards for all groups, and how best to combine mental health, incapacity and adult protection in one progressive and supportive legal framework.

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Mental Welfare Commission

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