The Independent Review of Learning Disability & Autism in the MHC&T act (2003)

The below outlines Specialist Learning Disability Service's (SLDS) response to stage 3 of the above review. The consultation document presents a significant number of proposals, many of which are interrelated with concurrent Scottish Government reviews, such as the review of the Adults with Incapacity Act and development of a supported decision making strategy. The response period has been limited, therefore it has not been possible to either comment on each and every point made in the document or submit a NHS Greater Glasgow & Clyde co-ordinated response (from the plethora of services potentially impacted). We thank the review team for their time to discuss some of the proposals presented within the consultation document.

How we understand autism, learning disability and mental health	
Proposals	Our response
• Scotland needs to move to understanding autism and learning disability as disabilities, not as mental disorders. The term 'mental disorder' should be replaced with 'impairment' (autistic impairment or intellectual impairment) to describe a permanent lifelong condition. The term 'disability' should be used to describe what results from the interactions between persons with impairments and attitudinal & environmental barriers that hinder full and effective participation in society. Disability can be temporary e.g. stress / distress.	We agree that Learning Disability and Autism should not be defined as 'mental disorder' within the Act. We welcome the differentiation between what is a 'lifelong' condition and what is potentially a temporary condition as a result of external factors which create barriers. Whilst we appreciate the suggested words of 'impairment' and 'disability' are dictated by agreed terminology, we do not think these are necessarily acceptable terms to use in Scotland as they may lead to misunderstanding and confusion (i.e. 'learning disability' is seen as a lifelong condition)
• Scotland's mental health services for autistic people and people with learning disability need to move to a human rights culture.	Agree, we would comment that there has been a recognition and shift towards a human rights culture across our services, however strengthening this is welcomed
• In Scots law, everyone is presumed to have legal capacity. It should not be possible to challenge the legal capacity of autistic people or people with learning disability.	We recognise that it is important to separate the intention of legislation from implementation. We are unclear how changing existing law / creating a new law will result in *changes to practice*. The current provisions within the act and the AWIA provide safeguards to ensure that decisions about treatment are individualised, offering protection to individuals who benefit from informed proxy decision making

Support for decision making	
• Scotland should make change to comply in full with a key right in the Convention on the Rights of Persons with Disabilities, the right to equal recognition before the law.	As yet, we have not been sighted on the Scottish Government strategy for supported decision making. Much of what is proposed within this consultation relies on an effective and robust system of supported decision making, including the availability of independent advocacy. We would welcome detailed proposals for supported decision making, what resources will be made available and how any suggested changes relate to Adult support and protection legislation prior to enable a full response. We found the narrative around the role of professionals in this section a little confusing. There is a suggestion that professionals should abide fully to the individuals statement of will, rights and preferences whilst conversely suggesting that the same professional can decide if the preferences would be in fact be in the 'best interest' of the person and therefore not act on them. Where treatment or care is urgent or where there is a need to act to reduce immediate risk / preserve life, we would welcome greater detail on how timely intervention could be delivered in these circumstances.
• To make it possible for autistic people and people with learning disability to have and use their legal capacity, Scotland would have to give strong support for decision making. A range of suggestions on how this support should be set up are given	As above, we would welcome more information on the SG strategy for supported decision making.
• Advanced statements should be replaced with a statement of **rights, will and preferences**, which would **not** be dependent on whether the person had mental capacity	We suggest that advance statements do not work well for people with learning disability. Our view is, should an individual be able to express a will or preference in any form, this then this should be acceptable in terms of the act.
• Human rights assessments would underpin what may benefit a	We suggest such assessments would have to meet the four rules of the proportionality test, namely legitimate ends, suitability, necessity,

person	and proportionality. Local areas would require guidance on what such assessment should contain, what would be considered a minimum, or a standardised national template would be welcomed. See below for further comments
• Individuals could challenge professional decisions which were believed to be disproportionate with the MWC via the MH tribunal service	This is a current feature of the existing act – we are not sure if a change is required. In terms of human rights it is clear that although an issue may be raised with the MHTS or MWC, these bodies would require 'powers' to compel a change to be made to a person's support or lack of support (as detailed further on in the consultation document)
• Independent advocacy would exist in an opt-out basis, placing a duty on public authorities to ensure provision, including non-instructed advocacy. Independent advocacy would be available at all times.	Independent advocacy is available across NHS GGC.
• A shift from 'best interests' to 'rights, will & preferences' would result in being unable to give medical treatment against the persons will.	Whilst we agree in principle, we suggest guidance would be required to cover when individuals become acutely unwell, for example experiencing an acute psychotic episode.
• Decision supports' should be introduced in law, such as unpaid carers, who should also be considered when a human rights assessment takes place	Whilst we agree that strengthening the rights of unpaid carers is critical, we suggest this should be developed with cognisance to any ASP considerations
• A standard for accessible communication, set by the MWC should be developed	We agree, whilst accessible information has grown in popularity, we would suggest that not all accessible information is developed in consideration of available evidence. Significant duplication exists and 'information' is often viewed in isolation to 'communication'. National standards and guidance would be welcomed, although we are not sure if this should be the remit of the MWC.
• A separate authorisation for each medical treatment including psychological interventions should exist	We are not clear if this would replace or amend current arrangements under section 47 of the AWIA? Studies have highlighted that adherence to Sec47 is challenging in practice, particularly across General Practice. We also need to be mindful that as an unintended consequence appropriate treatment is not delayed by any changes.

• MH tribunals should consider and authorise each form of medical treatment, including psychological interventions.	There is a risk of unintended consequences here - unnecessary delay in treatment could be introduced and the person centred element of treatment plans diminished.
• Work should be commissioned that effectively promotes the appropriate prescribing of psychotropic medications	We are unclear what this 'work' would entail, should this be academic research? Perhaps consideration to existing legislation e.g. the Misuse of drugs act may be beneficial
• Psychotropic medication should only be given when 'very significant benefit' can be proved and no alternative exists	What would be the test to prove 'very significant benefit'? There is a risk that more restrictive practices are used as an unintended consequence
• Regulations in law should be developed for *all* medical treatment including psychological interventions and psychotropic medications	We suggest that it would be impossible to list all conceivable medical treatments in law. Would this include any health intervention or only prescribing?
• Public authorities should have a duty to provide access to specialist health & social care services and environments – this should be a presumption in law	NHS GG&C promotes a 'people first' approach to specialist services and as such would firstly support individuals access to generic health services (ensuring reasonable adjustment). It would be the role of specialist services to support generic services to offer person centred care. Separate specialist services would only ever be offered for individuals who have complex challenges resulting from a medical condition or external factors
• Secure support services and safe spaces should be designed and staffed to enable people to come out of crisis	NHSGG&C / HSCPs commission a range of services which include contractual responses expected in crisis alongside statutory responses We work towards preventing crisis through provision of specialist community services. Our assessment and treatment services provide safe spaces for people who are acutely unwell. We are currently in the process of implementing a proactive redesign strategy which aims to shift the balance of care from crisis to prevention through a collaborative approach between our HSCPs and in patient services. This will focus on strengthened community responses and new ways of using our in patient resources to be more person centred for those at risk of admission. It would be an unusual

	position for legislation to detail individual service models and we would urge caution in pointing towards a particular model. However we do agree that a community based service / alternatives to support individuals who do not have acute MH needs, but require an environment out with their home is required. Ideally this should be a community solution, utilised by all, but available to support individuals in crisis with a focus on returning home as soon as possible.

Support, care and treatment	
• There should be a move away from a law that focuses on detention and compulsory treatment	We do not think that the current act does focus on detention and compulsory treatment. The Millan principles underpinning the act should prevent this. Detention and compulsory treatment form only a small part of the act. We agree that detention and compulsory treatment should only ever be considered as a last resort in response to acute phases of mental ill health
• A separate law that sets out the duties to public authorities may amend the current act	We are not clear of the benefits of introducing a new law at this stage and have significant reservations given the historical context of learning disability legislation. Given that the policy direction has been that of inclusion, we do have reservations in developing a separate piece of legislation for people with learning disabilities / autism
• Duties would encompass the right to health, dignity, accessibility, equality, access to specialist health care and non-discrimination	We would welcome if these new duties could enhance the existing act. The existing act recognises that individuals within high to medium forensic secure care have the ability to challenge excessive 'security' but this does not exist for individuals within assessment and treatment units. (Some of which is practice related e.g. supporting an individual who is detained (for treatment to maintain safety / wellness and be lawfully given) to move to a community setting via a CTO can be challenging). The present mechanism of 'recorded matters' has no authority to compel responsible commissioners to discharge individuals to a more suitable community environment

• People with learning disability and autistic people should have the right to regular, specialist health checks and the right to screening, assessment and diagnosis which is gender informed in the law	We welcome this, both for evidence based targeted health checks as well as where people who have learning disability / autism are excluded from existing GP contractual provisions e.g. annual blood monitoring, chronic disease management, screening etc.
• There should be a national autism service	We are not clear what the added value a national service for autistic people would be
• The law should require that all **children's service planning** is based on children's rights from the CRPD and the ECHR	We agree in principle, at present NHSGG&C specialist LD services are adult only
• Children should have the right to a co-ordinated support plan. **Statutory duties** should extend to **NHS boards** and **HSCPs**	Statutory duties do apply to NHS boards under the children and young people act for looked after children– we are not clear if this is this suggesting extending the act to include all children with LD / autism? If so we would be unable to comment until significant further detail was available.
• **Corporate parenting duties** should be extended in law	We are unclear if this suggests extending the Children and Young People (**Scotland**) Act 2014 definition of **corporate parenting** to include all children with LD / autism? We would be concerned of unintended consequences if so
• A clear statement in law, policy and practice should exist that restraint / seclusion for children are not treatment and can cause trauma	Agree however, in extreme situations a mechanism needs to exist to enable professionals to act safely and act lawfully
• Autistic people and people with learning disability should be given rights in law to have access to the support, care and treatment that they need.	From April 2012 the Patient Rights (Scotland) Act 2011 specified that health care services should consider needs, consider what would be of optimum benefit, encourage inclusive decision making about health and wellbeing, and provide information and support to do so – for everyone. Again we respectfully suggest that it may be that *existing* legislation requires greater scrutiny (in terms of adherence to) rather than a new law

• Support, care and treatment could be provided for women, children and offenders, in ways that respect human rights. • Duties would need to be placed on public authorities to make these rights real.	We do support that parents who have a learning disability or autism require more robust protection in law
• DPOs and people who have learning disability / autistic people should be involved in planning, developing and governing services	We involve people with learning disability in all aspects of care through a variety of forums – further detail on how this could be improved would be welcomed.

Where support, care and treatment happens	
• There should be a shift towards voluntary support and care that emphasises social support and care. • There should be a shift away from compulsory treatment in hospitals that emphasise medical treatment. • Places where support, care and treatment take place should include a new type of service which is called **secure support centres**.	The shift towards social care and support in the community has long been established. However we have a crowded marketplace of third sector providers, with gaps in service provision that requires to be addressed which leads to variance on how people are supported across Scotland. We need to be clear about the purpose and function of inpatient units, which are for the treatment of acutely unwell individuals who, due to the complexity and co morbidity of conditions require specialist service treatment responses and are not 'providers of last resort' We would urge extreme caution in suggesting congregate living circumstances for acutely unwell individuals and have significant concerns about the description 'secure support centres' and would not support this.
• Scots law should include a right to independent living that matches the CRPD, this should include duties on the SG and local authorities to ensure resources • A duty should be given to **H&SCPs** to make safe places available for autistic people and people with learning disability. These should be available in local areas	We agree that safe, community facilities should be available and should be resourced

• Scotland should move from a medical model to a disability model and introduce specialist secure support centres for people who need to be detained. A law should include duties on H&SCPs to provide these and include a duty for planning for discharge. These centres should be led and run by social work, nurses or OTs with input from all health professionals. They should operate similarly to secure children's care	It is not our view that services are currently orientated around a medical model. Learning disability policy currently sits within the health directorate of the Scottish government despite the clear equalities direction within the KTL strategy. In addition the historical context of service provision has led to the current situation. The majority of service provision is not delivered within a medical model. Where individuals are acutely unwell and require treatment (without or without detention) this should be delivered by the most competent and trained professionals. We would again urge extreme caution around the proposals to enshrine in law duties which in any way segregate people from the wider community. Generic services should improve and adjust and be complemented by specialist services
• A duty in law should be developed to ensure access to general health services	As above - From April 2012 the Patient Rights (Scotland) Act 2011 specified that health care services should consider needs, consider what would be of optimum benefit, encourage inclusive decision making about health and wellbeing, and provide information and support to do so – for everyone

How professionals make decisions	
• Scotland should make changes to move closer to compliance with the right to liberty and security.	A further shift towards a human rights culture is welcomed, however we are not clear how, as suggested, a MHO could complete a full human rights assessment in an emergency situation with an acutely unwell individual. HR assessments in principle should exist but not replace professional assessments (e.g. medical assessments)
• Scotland is not yet ready to end all detention on the basis of disability, or all compulsory treatment, in a safe way.	Agree - Figures published today (23rd October) by the MWC suggest 6,038 new episodes of compulsory treatment under the Mental Health Act in Scotland in 2018-19, the highest since the legislation came into force in 2003.The figures do not detail if there has been a rise in

	detention for people who have a learning disability / autism. Any move to end detention would require significant investment in preventative services
• Human rights assessments should be the basis for all professional decision making for autistic people and people with learning disability.	The detail of what a human rights assessment is requires definition. HR assessments are mentioned in the consultation in terms of proportionality and would be the duty of MHOs to complete. We are not clear of the resource implications. We do not agree that 'human rights assessments' could or should replace any medical / professional assessment of ill health
• New roles for a broad range of professionals.	We welcome the suggestion to examine the feasibility of extending the role of MHO to other professionals. We would not support a change in the RMO from what exists at present
• A 'proportionality' test in law should be called a 'human rights assessment'. MHOs would carry out such assessments when decisions are required for detention or compulsory treatment	We do not agree that MHOs (as exists at present) should carry this out. If an individual is thought to require detention, they will be acutely unwell, requiring the expertise of medical staff. There is current good practice where RMO's work with the MDT which should involve all 'relevant people' for the individual
• The existence of a disability should not justify a deprivation of liberty	Agree, nor should any form of behaviour that is labelled as challenging
• Psychiatrists and psychologists should not provide assessments of risk of offenders for reasons of pre-emptive detention	Risk assessments should be human rights based and multidisciplinary / multiagency including both the person / family/ carers and advocate. We are not aware of situations where an individual is detained 'pre-emtively' Health professionals will provide risk assessments to MAPPA for offenders who are also subject to detention under the MHA. Psychiatrists and psychologists often use Structured Clinical Judgement (SCJ) tools to produce risk assessments to inform risk management plans. Risk assessments are dynamic and take into account clinical factors e.g. response to treatment with the intention of reflecting change in risk with treatment. This is important when

	managing offenders with a learning disability / ASD / mental illness and it would be a real concern if clinicians were not involved in this process, particularly with patients they know very well for long periods of time. In contrast, Criminal justice services mostly use actuarial tools, which are often based on historical factors which do not change.
• Chief officers / chief social workers would be responsible officers with final responsibility from the MH tribunal	Disagree There is a risk of failure to understand the role of the multidisciplinary team, who have key skills in assessment and treatment of mental disorder with individuals who often have complex needs / diagnostic over-shadowing.
• An approved clinician role to extend the role of the RMO from psychiatrists may be required	It may, but would also require consideration to extend the role of MHO to other professionals The evidence the team have provided indicates that it has not worked well in England as there has been a less than 1% up-take. A non-medical RMO would also not have the same depth of training or experience with the complexity of disorders that may interact to contribute to the person's mental state.

How decisions are monitored	
• Scotland needs mental health law and services based on human rights. Autistic people and people with learning disability (duty on DPOs) should be routinely involved in developing, implementing and monitoring the law and services.	It would not solely be the responsibility of DPOs. There are a lack of DPOs for people with learning disability in Scotland
• The Mental Welfare Commission for Scotland and the Mental Health Tribunal for Scotland should have authority to protect the rights of autistic people and people with learning disability with new duties such as the authority to set, change and	We do not agree the role of the MWC should be extended. This has the possibility to cause conflict. The Human rights commission may have a role to set, monitor, inspect and grade standards? Would the role of existing bodies change? E.G. Health Improvement Scotland and the care inspectorate?

enforce human rights-based standards. • A range of suggestions on how human rights should be monitored are made.	

Offenders	
• Scotland should use 'intermediaries' to support suspects and defendants who have communication impairment.	"even with all the support and other reasonable adjustments, some people might still not be able to stand trial…" We are unclear how the role of an 'intermediary' relates to the role of the appropriate adult However, we would support provisions to improve participation at court for those with LD / ASD (or indeed any mental illness) and for disposal to be adapted depending on their needs. Individuals with borderline / mild LD can often manage reasonably well in prison, and we support any improvements to disability accessibility / adaptations in the prison environment that would be of benefit to the wider prison population.
• A change to how disability is understood in criminal law is required. This change could make it possible for person to be held responsible for an offence, but also to have adapted consequences that take account of the person's disability.	The crown currently considers proportionality and mitigating factors when deciding culpability and in sentencing guidelines, although these could be reviewed further. The suggestion of adapted consequences for those who offend with a disability (LD / ASD) could apply to everyone e.g. mentally ill offenders too.
• Punishment, treatment and support to stop offending should be clearly separated out in law for autistic offenders and offenders with learning disability.	Unsure Potentially, having a law only for LD / ASD would be open to legal challenge on basis of inequality and if changes are proposed for this

	group then this would end up being applied to all those with a disability. Therefore, there are potential far-reaching consequences – that are not limited to those with LD / ASD – that require more in-depth consideration.
• Punishment should not be longer for these offenders than for any other offenders.	Agree In theory we agree but current mental health legislation would need to be reviewed as for serious offences disposed of e.g. by CORO there is 'no limit of time' (although the criteria are reviewed annually and subject to appeal to MHTS). Risk needs to have been demonstrated to have reduced significantly before conditional discharge / revocation of the restriction order. This is important for public protection but patients often struggle with not having an 'end date' to their detention. There would need to be careful consideration of the implications of changing current practice and how the associated risks would be managed e.g. for those with ongoing risk of sexual violence etc.

Where support, care and treatment happens for offenders	
• Rehabilitation should usually happen in the community, for offences that would usually lead to community rehabilitation for anyone else.	Agree
• Offenders should be given support, care or treatment in the community or in rehabilitation centres, not in hospitals.	The review of forensic services in Scotland is underway. It is difficult to comment on this without the conclusion of this review
• Prison should only be used for autistic offenders or offenders with learning disability when it is specially designed or adapted to meet the person's needs.	It is difficult to see how one group of prisoners could be separated out from the rest of the population. One could argue, beyond deprivation of liberty all prisoners human rights can be breached within a custodial setting and that the prison system needs to also reasonably adjust services to meet the needs of the whole prison population

What this means for the law

The Independent Review of Learning Disability & Autism in the MHC&T act (2003)

• Autism and learning disability should no longer be defined as 'mental disorders' in Scotland's Mental Health Act.	Agree
• Scotland should develop a new law to give 'positive rights' for support, care and treatment to autistic people and people with learning disability.	Disagree
• Changes are required in criminal law.	Unsure
• Scotland should prepare to end detention on the basis of disability, and to end compulsory treatment, at some time in the future.	On the basis of 'disability' as defined in the consultation - agree However, at times reading the report, and this may be because the report was essentially in plain English. it felt as if there was a misunderstanding of current mental health legislation in that services do not simply detain on basis of disability but have to consider all criteria ofr detention, as well as the Millan principles underpinning the Act.