

Consultation Response

Scottish Mental Health Law Review Consultation Submission

The Scottish Commission for People with Learning Disabilities May 2022



Background

The Scottish Commission for People with Learning Disabilities (SCLD) is an independent charitable organisation and partner to the Scottish Government in the delivery of Scotland's learning disability strategy, The keys to life and the Towards Transformation Delivery Plan.

SCLD is committed to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities have opportunities and are empowered to live the life they want in line with existing human rights conventions. SCLD believes that the discrimination and barriers faced by people with learning disabilities and other disabled people are not inevitable. These barriers stop people with learning disabilities and other disabled people being included in society and participating on an equal basis.

Section 1. Introduction:

SCLD welcomes the opportunity to respond to the Independent Scottish Mental Health Law Review (SMHLR) proposals.

We believe that Scotland's mental health and capacity law and the wider legislative framework requires radical change to respect, protect and fulfil the human rights and well-being of people with learning disabilities. As we have previously argued¹, we believe current Scottish mental health and capacity law fails to adequately promote and protect the human rights of people with learning disabilities and leads to practices which are inherently discriminatory towards them.

¹ <u>SCLD response to Stage 1 of SMHLR (2020)</u>

Since the Mental Health (Care and Treatment) (Scotland) Act 2003 (2003 Act) was enacted there have been significant developments in human rights law and practices, not least the United Nations Convention on the Rights of Persons with Disabilities (CRPD)². All legislation in Scotland must be compatible with the European Convention of Human Rights (EHRC)³, which as a 'living treaty' evolves over time and has been influenced by the CRPD as case law has developed.

Significantly, following the recommendations of the National Taskforce for Human Rights Leadership⁴, the Scottish Government has announced plans for a Human Rights Bill⁵ which will incorporate four human rights treaties, including the ICESCR (which includes the right to equally enjoy the highest attainable standard of physical and mental health (Art 12⁶)) and the UNCRPD, into Scots Law. SCLD believes that this incorporation of human rights treaties into Scot's law necessitates:

- **Change led by people with learning disabilities:** Full involvement of people with learning disabilities (rights bearers) in developing, implementing and monitoring the laws and policies that support Scotland's commitment to the UNCRPD and other human rights standards.
- A 'paradigm shift': People with learning disabilities must be equal citizens whose rights are respected, protected, and fulfilled, have equal standing before the law, and support to make full use of their legal capacity.
- Equality and non-discrimination in how people experience their rights: A characteristic such as disability should never be used to justify a limit on human rights.

² Convention on the Rights of Persons with Disabilities (2006)

³ Scotland Act 1988 and Human Rights Act 1998

⁴ National Taskforce for Human Rights Leadership

⁵ <u>Human Rights Bill</u>

⁶ International Covenant on Economic, Social and Cultural Rights | OHCHR

- **Supported decision-making:** Supported decision-making must ensure that people with learning disabilities' rights, will and preferences are respected on the same basis as other people's rights, will and preferences.
- **Proportionate decisions:** Any limits to rights must be applied equally for all people. Limits must not discriminate against people with learning disabilities in any way.

We recognise that this 'paradigm shift' presents numerous challenges from both a legislative and political perspective and will require a significant shift in both culture and practice supported by significant additional resources. We are therefore extremely disappointed that the SMHLR Review has failed to address, in any substantial way, some key recommendations of the Independent Review of Learning Disability and Autism in the Mental Health Act (Rome Review)⁷.

The Rome Review concluded that people with learning disabilities are poorly served by current legislation and that the Mental Health (Care and Treatment) (Scotland) Act 2003 had led to specific negative effects on the human rights of autistic people and people with learning disabilities. The report⁸ made extensive recommendations, including:

- Learning disability and autism be removed from the definition of mental disorder in Scotland's Mental Health Act.
- Learning disability and autism should be defined in a new law which supports access to positive rights and gives duties to public services.
- Decisions for detention and compulsory treatment should not be made on the basis of learning disability or autism

⁷ The Independent Review of Learning Disability and Autism in the Mental Health Act (2019): Final Report

⁸ <u>The Independent Review of Learning Disability and Autism in the Mental Health Act (2019): Final</u> <u>Report</u>

• A new commission be established to promote and protect the human rights of autistic people and people with learning disabilities across all settings.

People First (Scotland) state that their argument for legislation covering people with intellectual impairment is to address the historical (and current) discrimination, abuse, denial of life opportunities and (apparently lawful) withholding of our human rights on the basis of having that characteristic alone⁹.

It is useful to remember that the Rome Review produced its findings in the context of the 40 recommendations of the Equalities and Human Rights Committee Inquiry, published in November 2018, which made recommendations for Government, Parliament, local authorities, the SHRC and EHRC.¹⁰ The progressive realisation of rights and the fulfilment of duties requires people with learning disabilities to be removed from mental health law as their inclusion in this category is the result of a society which disables them institutionally and culturally.

We are clear that the SMHLR's 'preliminary view that this new, human rights based legal framework should apply to persons with mental illness, learning disability, personality disorder, dementia, autism and other types of neurodiversity¹¹ is not in accordance with the Rome recommendations, nor is it compatible with the UNCRPD and ICESCR. In fact, in line with article 2 of the UNCRPD, SCLD believes the inclusion of learning disability within the understanding of 'mental disorder 'in this act constitutes disability-based discrimination. The UNCRPD Article 2 defines this as 'any distinction, exclusion or restriction based on disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an

⁹ People First submission to SMHLR (2022)

¹⁰ Getting Rights Right: Human Rights and the Scottish Parliament | Scottish Parliament

¹¹ SMHLR consultation March 2022

equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.¹²

Given the ongoing work to incorporate the UNCRPD into Scottish law and the analysis of Scottish law compliance which may follow, it is now critical the SMHLR's final report properly addresses the recommendations outlined in the Rome Review¹³. In doing this the Review should endorse the removal of learning disability from the definition of a mental disorder and its definition within new legislation which support access to positive rights, gives duties to statutory bodies and provides equity in law.

We also believe the Scottish Government has a responsibility to respond to the IRMHA recommendations as part of the SMHLR process and should work to facilitate the necessary connections and ensure alignment with the Scottish Human Rights Bill and the Learning Disability, Autism and Neurodiversity Bill.

Fundamentally, we understand that people with learning disabilities may be detained if they are experiencing mental ill health, but we do not believe they should face a lower legal burden for the suspension of their rights and liberty than any other citizen as this practice would be discriminatory. Instead, there is currently a unique opportunity for significant change to the existing legislative framework to achieve transformational change and positive outcomes for people with learning disabilities whilst ensuring they have access to appropriate support which respects their human rights. It is critical to the lives of people with learning disabilities that this opportunity is not missed.

¹² Article 2 UNCRPD (2006)

¹³ The Independent Review of Learning Disability and Autism in the Mental Health Act (2019): Final Report

Section 2. Purpose of the law:

What are your views on the purpose and principles that we are proposing?

What do you think about the approach that we are proposing for Scottish Government to meet core minimum obligations for economic, social, and cultural rights in this area?

The proposals set out the purpose of mental health and capacity law as being '*to ensure that all the human rights of people with mental disorder are respected, protected and fulfilled*¹⁴. While SCLD completely supports the ultimate objective of respecting, protecting, and fulfilling human rights, we do not believe that mental health law should be the primary means of achieving this for people with learning disabilities. We believe that attempting to fulfil and protect the human rights through the prism of mental health legislation runs the risk of further entrenching underlying prejudices and social attitudes towards people with learning disabilities.

Indeed, SCLD believes that people with learning disabilities are currently failed by mental health law and the wider system. The historic policy of institutionalisation and segregation resulted in societal *'othering'*¹⁵ and denied people with learning disabilities their citizenship and rights. For SCLD, the idea of automatically including a group of disabled people within legislation which can be used to restrict individual rights and freedoms based on disability could be argued to be direct discrimination under both Article 2 of the UNCRD and Equality Act¹⁶. If the wider population would not have their human rights progressively realised through mental health

¹⁴ SMHLR consultation March 2022

¹⁵ Parr & Butler (1999) Geographies of Illness, Impairment and Disability

¹⁶ Equality Act (2010)

legislation, we do not see a clear rationale for including all people with learning disabilities within the scope of the legislation receptive of their mental health needs.

Furthermore, the impact of medicalised deficit models of disability has been long lasting. People with learning disabilities continue to experience multi-layered trauma, exclusion, stigma, poor outcomes, and barriers to accessing rights across a wide range of domains including active citizenship, full engagement in civil and public life and a lack of access to education¹⁷, employment¹⁸, relationships¹⁹, and family lives²⁰.

People First (Scotland) state that "our argument for legislation covering people with intellectual impairment is to address the historical (and current) discrimination, abuse, denial of life opportunities and (apparently lawful) withholding of our human rights on the basis of having that characteristic alone."

Indeed, ICECSR General Comment 20, on Article 2(2)²¹ recognises that eliminating discrimination in practice requires paying sufficient attention to groups of individuals which suffer historical or persistent prejudice instead of merely comparing the formal treatment of individuals in similar situations. States Parties must therefore immediately adopt the necessary measures to prevent, diminish and

¹⁷ ENABLE (2016) #IncludED in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability

¹⁸ <u>McTeir et al (2016) Mapping the Employability Landscape for People with Learning Disabilities in</u> <u>Scotland</u>

¹⁹ <u>SCLD (2018) Safe and Healthy Relationships: Empowering & Supporting People with Learning Disabilities</u>

²⁰ <u>SCLD (2018) Children's Rights: Consultation on incorporating the UNCRC into our domestic law in</u> <u>Scotland</u>

²¹ <u>ICECSR General Comment 20 (2009)</u>, on Article 2(2) non-discrimination together with progressive realisation

eliminate the conditions and attitudes which cause or perpetuate substantive or *de facto* discrimination.

The existence of these barriers is completely at odds with the UNCRPD which requires that people with disabilities are entitled to enjoy all human rights on an equal basis with others to enable their full and effective participation in society. Critically, this requires not only promotion of rights but also the active removal of barriers which prevent the full and equal enjoyment of human rights²². This was recognised by the Rome Review, and as stated, we are extremely disappointed that the SMHLR proposals have not meaningfully addressed the key recommendations of the Rome Review. It is regrettable that more than three years on from the IRMHA report, the SMHLR has been unable to take a definitive position or offer any clarity around the status of people with learning disabilities in relation to the 2003 Act.

Since the publication of the Rome Review, there have been several further developments which create an architecture for human rights in Scotland in addition to the Human Rights Act 1998 and provisions in the Scotland Act 1998. The collective impact of these developments is likely to lead to significant changes in the existing legislative and accountability frameworks which impact the lives and protect the rights of people with learning disabilities. These are:

• Legislation for a National Care Service following the review of adult social care²³

 ²² Convention on the Rights of Persons with Disabilities (2006)
²³ Review of Adult Social Care In Scotland

- A Human Rights Bill²⁴ to incorporate four human rights treaties, including the • UNCRPD and ICESCR, into Scots Law following the recommendations of the National Taskforce for Human Rights Leadership Taskforce²⁵
- Giving domestic effect to the UNCRC through the United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Bill
- A Learning Disability, Autism and Neurodiversity Bill and Commissioner • detailed in the Programme for Government 2021-22²⁶

We believe these legislative developments offer an opportunity for a radical reframing of the legislative landscape which impacts the lives of people with learning disabilities and view these as critical to protecting and respecting the social, economic, and cultural rights of people with learning disabilities. An essential component of this reframing must be an end to the automatic inclusion of people with learning disabilities within mental health legislation. As stated, it is SCLD's view that these legislative developments potentially conflict with the direction of SMHLR proposals and could open the door to legislative challenge and any subsequent Mental Health Bill failing to be approved as competent under Section 29 of the Scotland Act 1998.

We note the SMHLR Review's position that they are not only concerned with the rights of people who receive care and treatment without their consent, but we do not believe that mental health and capacity law could or should be charged with securing the full range of rights for people with learning disabilities. SCLD notes that whilst the consultation states that capacity law has little to say about economic,

 ²⁵ National Taskforce for Human Rights Leadership
²⁶ Programme for Government 2021-22

social and cultural rights, the proposals in Chapter 2 appear to relate mainly to the 2003 Act²⁷.

SCLD supports the solution proposed by the Rome Review that learning disability should be defined in separate legislation which is designed to support access to positive rights and give duties to statutory bodies to provide equity in law. However, where someone with a learning disability or an autistic person has mental ill-health that requires care, support or treatment over and above their lifelong disability, then they should continue to enjoy the care, support and protection from human rights based mental health law in the same way as any other person. Where people with learning disabilities do have their rights limited in these circumstances, we believe there is a need for strengthened provisions and duties to promote and protect social, economic, and cultural rights, particularly with respect to transitions to community living.

SCLD has previously expressed concerns about the lack of evidence on the impact of the duties in sections 25-27 of the 2003 Act on delivery at a local level as well as a lack of monitoring or oversight²⁸. Sections 25-27 place duties on local authorities to provide care and support services to support independent living and travel, promote wellbeing and social development and training and employment assistance for people over school age²⁹. These sections have had little or no impact on any of these issues for people with learning disabilities since the law was enacted. In fact, there is significant evidence that people with learning disabilities do not fully enjoy the rights these duties are designed to support³⁰.

²⁷ SMHLR consultation March 2022

²⁸ <u>SCLD response to Stage 1 of SMHLR (2020)</u>

²⁹ <u>Mental Health (Care and Treatment) (Scotland) Act 2003</u>

³⁰ <u>SCLD response to Stage 1 of SMHLR (2020)</u>

Given this, in the context of mental health legislation, SCLD supports the reframing of these duties to set out clear and attributable duties on NHS Boards and local authorities specifically in relation to mental health support. However, there is also a clear need for wider legislative measures that can fulfil and protect the social, economic and cultural rights of people with learning disabilities and address the societal barriers and disadvantages the experience.

We believe the reframed duties should include clear consequences for failure to comply both in terms of regulation and in an accessible enforcement route for people and their carers/families as well as measures to ensure that these sections are specific to the remit of the legislation.

SCLD agrees with the Review that for care, treatment and support to be fully compatible with human rights standards, including the UNCRPD, change is required at a political, societal and cultural level to engender a shift away from viewing mental health law as simply authorising and limiting non-consensual interventions towards proactive support for people experiencing poor mental health to live well.

With respect to people with learning disabilities, it is critical that mental health services are available, accessible, acceptable and of good quality. It is critical that community services are adequately resourced, and that people have appropriate access and rights to health checks, screening, assessment and diagnosis, alongside national standards for accessibility. This must be accompanied by genuine participation and engagement for people with learning disabilities at all levels of service delivery, and in the development of law, policy, and practice.

As a society Scotland has much to do to deliver on these ambitions. Any system will encounter challenges around insufficient training and a lack understanding in the practice of human rights and staff shortages. Pressured budgets will create further layers which create a gap between intent and practice. However, decisive and unambiguous legal reform will change culture as well as practice and give effect to ICESCR General Comment 20³¹ and Article 2 of the UNCRPD.³²

SCLD believes the process to date has been disadvantaged by a lack of meaningfully disaggregated statistical information. This lack of data is an issue for policy development and legal reform given States Parties' obligations under Article 31 of UNCRPD to "collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention". There is also a duty to disseminate and learn from this information which should be 'disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations … and to identify and address the barriers faced by persons with disabilities in exercising their rights." (Article 31 (2)-(3)³³

Summary of Key Points:

- Recently proposed legislation offer the opportunity for more radical change which positively protects and respects the social, economic and cultural rights of people with learning disabilities.
- The urgent need to remove people with learning disabilities from the term 'mental disorder' in line with the Rome Review Recommendations.
- **3.** Learning disability should be defined in a separate legislation which is designed to support access to positive rights and give duties to statutory

³¹ <u>ICECSR General Comment 20 (2009)</u> For a similar definition see art. 1, ICERD; art. 1, CEDAW; and art. 2 of the Convention on the Rights of Persons with Disabilities (CRPD). The Human Rights Committee comes to a similar interpretation in its general comment No. 18, paragraphs 6 and 7. The Committee has adopted a similar position in previous general comments. ³² Paras 7-8 ICESCR General Comment 20 <u>Treaty bodies Download (ohchr.org)</u>

^{7&}lt;sup>33</sup> Convention on the Rights of Persons with Disabilities (CRPD) | United Nations Enable

bodies to provide equity in law (ref Human Rights Bill and Learning Disability, Autism and Neurodiversity Bill).

- 4. Where someone with a learning disability or an autistic person has a mental illness over and above their lifelong disability, then they should enjoy the care, support and protection from revised human rights based mental health law.
- **5.** Strengthen provisions and duties for promoting and protecting social, economic, and cultural rights including transitions to community living.
- 6. Ensure appropriate access and rights to health checks, screening, assessment and diagnosis, alongside national standards for accessibility.
- **7.** Provide regulatory consequences for failure to comply which work alongside accessible enforcement procedures for right holders.
- Provision in law to collect, learn and disseminate from meaningful and accessible disaggregated statistical information in line with CRPD Article 31.

Section 3. Supported Decision Making

What are your thoughts on our recommendations for a wide ranging supported decision making scheme?

SCLD welcomes the proposals for the development of a comprehensive regime of supported decision making. For people with learning disabilities, SCLD sees the role of a *'decision supporter'* and provision for a statement of *'Rights, Will and Preferences'* as important additions in supporting people to make decisions and exercise their legal capacity.

We believe these can be crucial elements in seeking to reframe the current legal framework from one that is mainly restrictive in nature towards an enabling piece of legislation, which is genuinely rights based and places much greater emphasis on recognising an individual's rights, will and preferences.

This in line with the recommendation by the United Nations Committee on the Rights of Persons with Disabilities in 2017 on the need for the UK to abolish substitute decision-making practices, build supported decision-making in legislation, policy and practice.³⁴ Article 12 of the UNCRPD requires States Parties to *'provide access by persons with disabilities to the support they may require in exercising their legal capacity and that measures relating to the exercise of legal capacity must ensure respect for the rights, will and preferences of the person'.³⁵ It also requires States Parties to create appropriate and effective safeguards for the exercise of legal capacity and these must include protection against undue influence.³⁶*

³⁴ Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland (2017)

³⁵ <u>Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD in Scotland</u>

³⁶ Convention on the Rights of Persons with Disabilities (2006)

Therefore, in our view, robust supported decision-making structures accompanied by a national framework and the necessary resources to support these are paramount in realising the paradigm shift that incorporation of the UNCRPD vis-àvis the Human Rights Bill requires.

It is critical that any changes in law are accompanied by strong rights and attributable duties to support access to decision making, together with appropriate safeguards to ensure that the rights, will and preferences of learning disabilities are respected. This includes maximising decision-making autonomy whenever interventions are being considered under mental health and capacity legislation.

In these circumstances, we believe every effort should be made to support someone to express their "will and preferences" and decide before any other type of intervention is considered. We understand the Review's position that there will be circumstances that may necessitate a need for non-consensual interventions and treatment and that these should be provided for in law. However, we believe that it is imperative individuals have the necessary support to enable their voice to be heard and respected in these situations.

This necessitates a well-resourced supported decision-making framework with a wide range of options to help people with learning disabilities and others exercise their legal capacity. It also necessitates appropriate and effective safeguards to prevent abuse in this regard³⁷. We believe assessing the quality of support and its alignment with the principles of supported decision-making should be an important safeguarding feature of the framework.

People First (Scotland) have produced a Framework for Supported Decision-Making³⁸ which sets out a template for the role of a decision supporter and how to

 ³⁷ Convention on the Rights of Persons with Disabilities (2006)
³⁸ People First (2017) Framework for Supported Decision Making

understand a person's support needs and constructing methods of support to help people understand, remember, weigh up alternatives and consider consequences. We believe this should inform the development of a national framework for Supported Decision-Making.

Given the power imbalances and the potential for abuse of human rights, we consider there needs to be significant checks and balances as well as a real time duty to keep accurate records.

Summary of Key Points:

- 1. The role of a 'decision supporter' and statement of 'Rights, Will and Preferences' constitute important elements of the framework for people with learning disabilities.
- 2. The SDM framework must be robust, well-resourced and supported by a national framework.
- **3.** There is a need for strong rights to access and attributable duties on public bodies to provide decision making support, together with appropriate safeguards to ensure that rights, will and preferences are respected.
- **4.** Ensure independent oversight to ensure rights are upheld and duties

What do you consider would be the barriers to this?

How do we mitigate against undue influence or pressure in SDM generally?

SCLD recognises that implementing an effective supported decision making regime in practice will be a challenge which requires leadership at a national level, training across a range of professions and sustained resourcing at a local level.

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Independent advocacy is significantly underfunded in Scotland at present, despite existing statutory requirements.³⁹ Therefore, widening the availability and access to independent advocacy as a key feature within support for decision-making will require a significant commitment to additional long-term funding. We believe there also needs to be accredited, high quality training on a range of support and communication skills for independent advocates.

There will also be a requirement for much greater capacity building across a wide range of professionals and non-professionals to facilitate access to effective support for decision-making for people with learning disabilities. Building the capacity of people to perform the new decision supporter role will be fundamental to the success of the new supported decision-making scheme. It is essential that this is appropriately resourced to ensure that those providing support have the necessary training and skills to support individuals effectively.

Support for decision-making will take many forms and effective implementation will require a shift in culture and mindset across all professions and organisations as well as among families and people with learning disabilities themselves. It will be necessary to work hard to overcome potential obstacles to support decision-making such as risk averse organisational cultures, time constraints and limited staffing.

Some people with learning disabilities will have limited experiences of decision making, and it is essential they and their supporters understand the aims, principles and process of supported decision-making. The models highlighted in *Supported Decision-Making: Learning from Australia*⁴⁰ evidence the importance of building the knowledge and skills of family members and friends as an effective way to support and sustain decision-making ability. However, many people lack these natural

³⁹ SCLD (2018) A Stronger Voice? A scoping study of independent advocacy for people with learning disabilities ⁴⁰ Supported Decision making: Learning from Australia' Killoop, L. (2016)

⁴⁰ *'Supported Decision-making: Learning from Australia'*, Killeen, J. (2016)

support networks and there should not be an assumption that everyone has supportive and trusted family members or friends who are able to perform his role.

Research in Australia⁴¹ found that parents were conflicted in the degree of influence they exerted and highlighted a number of potential barriers which posed challenges to support for decision making with people with learning disabilities. These included:

- perceived limited awareness of possibilities.
- poor insight about options.
- limited understanding of constraints and consequences.

The same research also identified factors that are most consistently identified as contributing to a rights-based approach to supported-decision making:

- a trusting relationship between a supporter and a person with intellectual disabilities.
- knowledge about the person.
- familiarity with their modes of communication.
- commitment to their right to participate in decision making and positive attitudes toward risk.

Therefore, the quality of decision-making support that people receive will directly influence their ability to exercise legal capacity. A key element of this is an emphasis on relational quality and fostering relationships based on equality, respect and trust, alongside reformed legislation.

⁴¹ Bigby, C et al (2021) Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences

Summary of Key Points:

- **5.** A requirement for a significant commitment to additional long-term funding for independent advocacy supported by accredited, high-quality training on a range of support and communication skills.
- 6. Adequately resourced capacity building across a wide range of professionals and non-professionals including around the new decision supporter role.
- **7.** A commitment to culture change to overcome obstacles such as risk averse organisational cultures and parental attitudes.
- 8. An ongoing emphasis on quality of support and relationships based on equality, respect, trust.

What are your thoughts on the creation of a Centre of Excellence for Supported Decision Making?

Given the cross-cutting nature of the proposed Centre for Excellence it will be essential that there is further engagement and consultation to ensure it meets the needs of all potential stakeholders. Furthermore, it is critical that a Centre of Excellence has sufficient resources to provide expertise, training and guidance to facilitate the capacity building and supports the development supported decisionmaking in Scotland. Equally it must impact change at a local level and not in any way delay the process of change.

We recommend the development of a national SDM training programme, on a similar basis to the 3-tiered National Trauma Training Programme. Some key features of this, at different levels, should be to cover the aims and principles of supported decision-making, explain its process and develop the capacity of those who provide support for decision making. This should include an emphasis on looking beyond the outcome of the process to reflect on how support can influence

and encourage individual agency. The input of people with learning disabilities should be central in developing this.

SCLD also notes Scotland's Inclusive Communication Hub and its role in working with right holders and duty bearers.⁴² Findings from the recent report '*Mental Health, Sensory Loss and Human Rights', A transition* report also call for sensory literate services and action to address sensory poverty which causes poor mental health and stops people accessing support⁴³.

We believe there could be more detail in the proposals about the role of accessible communication as part of a comprehensive supported decision-making framework. We also believe that Scotland should set standards for accessible communication for people with learning disabilities and others and we think this could be a possible role for a Centre for Excellence. These standards should be rights-based and informed by people with lived experience. Additionally, we believe a Centre for Excellence could provide a centre of expertise for a range of communication tools including Easy Read, Talking Mats and Eye Gaze.

Summary of Key Points:

- **9.** There is a need for a well-resourced Centre of Excellence to provide leadership, expertise, training and guidance to building capacity around supported decision-making
- **10.** Development of a national SDM training programme, on a similar basis to the 3-tiered National Trauma Training programme.
- **11.**Set national standards for accessible communication and expertise in a range of communication tools hosted within the Centre of Excellence.

12. Propose a timeframe for set up and delivery.

⁴² <u>Welcome to the Inclusive Communication Hub | Inspiring Inclusive Information in Scotland</u>

⁴³ <u>Mental Health, Sensory Loss and Human Rights', A transition Deafblind Scotland et al (2021)</u>

Section 4. The Role and Rights of Unpaid Carers:

SCLD would welcome consideration of a return to the Milan principle⁴⁴ of Respect for Carers as a stated principle. We believe to do so is a clearer recognition of the value of unpaid carers and the role they play for some individuals.

SCLD welcomes the recommendation for a framework to identify and work with unpaid carers of all ages and improving communication in general. SCLD believes the framework within the *Triangle of Care* is an excellent starting point. The *Triangle of Care* recognises transcultural issues that may need to be taken into account, in particular for carers from black, Asian and minority ethnic communities.

However, SCLD believes it is important to recognise that people with learning disabilities, while more often than not viewed as the recipient of care, may be carers themselves.⁴⁵ Often, they may not see themselves or label themselves as such, and so consideration of how to engage and communicate with unpaid carers takes on even greater importance. These considerations must start from the recognition that accessible communication that meets the needs of the unpaid carer will be starting point.

What are your views on mandatory Carer Awareness training for all mental health staff?

SCLD supports the recommendation of mandatory Carer Awareness Training for all mental health staff. It is important that *all* staff who may come into contact with a carer should have this training – including senior staff. This training should be for everyone who may come into contact with carers of someone with a mental disorder, learning disability or autism, not just for nursing staff.

⁴⁴ Report on the Review of the Mental Health (Scotland) Act 1984, (2001)

⁴⁵ Nice Guideline (2018) <u>Care and support of people growing older with learning disabilities</u>

While SCLD would support any recommendation made by the review for mandatory Carer Awareness Training, we would caveat that by stating that this training needs to be truly co-developed and indeed delivered jointly with unpaid carers and the organisations who work with and for them. As well as the national and local carers organisations, it is pivotal that PAMIS is closely involved so as to ensure the needs of carers of those with profound learning and multiple disabilities are fully understood.

PAMIS support people with profound and multiple learning disabilities (PMLD) and their family carers. People with a PMLD have a profound learning disability and, in addition, they will have one or more of the following:

- Physical disabilities that seriously limit their ability to undertake everyday tasks and usually restrict their mobility with the majority being life-long wheelchair users;
- Sensory impairments with vision and/or hearing affected;
- Communication is typically non-verbal, though some will have limited speech;
- If non-verbal, all have the capacity to communicate in a variety of non-verbal ways;
- Some will also have communicative behaviour which may challenge services;
- The majority will require 1:1 24-hour care and many will require 2:1 care to be provided.

Some people with PMLD will also have healthcare needs, which are often extensive and complex and may be life threatening.

Family carers, whom PAMIS support, provide intensive long-term care, and have the knowledge and understanding of their son or daughter. They are the experts in the needs of their relative and the way care and support should be delivered to best meet their needs. For those with challenging behaviour, parents know the triggers and a challenging behaviour plan is often already available and in place. A human rights approach that maintains the persons dignity and respect should always be the

norm. Involving carers is an absolute must when making any decisions about a person's welfare, and where a guardianship order is in place the person's named guardians have a legal right to be part of any welfare and in many cases financial discussion. SCLD believes this should also be the case for decision making representatives, if this role is introduced as part of a new decision-making framework.

Partnership working that is inclusive and engages meaningfully with carers can be highly beneficial for both parties. Unpaid carers will feel that their understanding and knowledge is valued, and shared information will better inform staff who will then provide appropriate care that meets the needs of the person being cared for. Improved working and practice in the workplace will benefit all.

PAMIS provides training on a number of topics relevant to the needs of the individuals and families they work with. One course that may be highly relevant in this context is:

Understanding Challenging Behaviour.
<u>https://pamis.org.uk/site/uploads/understanding-communication-and-behaviour-flyer.pdf</u>

For people who are non-verbal the use of digital passports is another useful tool. The PAMIS passport is a simple, easy to use, flick-through e-book that can be created and displayed on tablet devices, computers and phones. Each PAMIS passport contains information about one person and uses video, photography, sound and text to help that person express their needs. The passport, uniquely, is owned by the individual and is shared with those they choose to share it with. The initiation and development of the passport might come from family carers, paid carers, practitioners, and individuals themselves.

The development process has often been used as a way of building a truly person led approach with people who need extra support. The passports are freely available to anyone who needs them. <u>https://pamis.org.uk/services/digital-passports/</u>

Any mandatory awareness training must recognise that carers are not simply a homogenous group and have many intersecting characteristics. As stated above, many people with learning disabilities are carers themselves. It will be important that training takes into account any needs arising from this, including accessible communication needs.

Co-developing and delivering this training will require adequate resource – it is imperative that this resource burden is *not* expected to be met by unpaid carers or the organisations that work with and for them.

What are your views on information sharing with unpaid carers of all ages?

Young carers should have important and relevant information shared with them. Depending on age and sensitivity of information and if acceptable, support organisations for young carers could be contacted to provide additional emotional support.

Carers, regardless of age, should be involved and informed at all stages of the person's care pathway.

What is needed to ensure mental health services identify and engage with young carers?

Engaging with young carer organisations who will be aware of some young carers in their area. However, as many young carers are hidden, identification of young carers within the family of the person who is being treated, should be made at time of admission. Very often a regular visitor will be the person's significant carer at home. Regular open dialogue with relevant organisations, across all sectors, should be considered.

What are your views on including unpaid carers in discharge planning and processes, as stated in the Carers (Scotland) Act 2016?

SCLD is supportive of including unpaid carers in discharge planning and processes. They know the person best especially if they are family members. The family carer or relevant other will be key in ensuring the person's care continues as they will often be the person's main support in the community setting. Not including them devalues their role as carers. Ensuring family/unpaid carers involvement in any discharge discussion respects the role of the unpaid carers who are crucial members of any post hospital discharge team and helps ensure re-admission is avoided.

Including unpaid carer involvement in discharge planning withing the proposed framework to identify and work with unpaid carers would be a welcome step towards this. It is important to state that unpaid carer involvement in discharge planning must not substitute the wishes of the person themselves in relation to their discharge.

What needs to happen to ensure unpaid carers of all ages are respected and valued?

Unpaid carers of all ages will only be respected and valued when there is a better overall understanding of the unpaid carer role;

- The reality of the caring role and lived experience;
- The economic and societal value and contribution unpaid carers make;
- The significance of the relationship between the carer and the cared for person;
- Equal partners in care and respecting each other's role;

- The fact that we will no doubt require care at some point be it temporary or permanent;
- Some of us will become unpaid carers;
- We need to get it right and ensure we are all valued and supported well in whatever role we find ourselves in now and in the future.

Summary of Key Points:

- **13.**Consider return to the Millan principle of Respect for Carers as a stated principle.
- **14.** Ensure any framework to identify and work with unpaid carers recognises carers are not a homogenous groups.
- **15.** Ensure any framework also includes unpaid carers in discharge planning.
- **16.** Young carers should be identified at the time of admission.
- **17.** Ensure that mandatory Carer Awareness training is co-produced with relevant groups including PAMIS and make adequate resource available for this.

Section 5. Human Rights enablement – a new approach to assessment:

What are your thoughts on the proposed HRE framework? What barriers do you

As currently constituted, we believe the list of circumstances that should trigger an HRE would lead to a very broad application of HRE process. In our view, they are too wide-ranging and the thresholds for applying a HRE are vague. In order to be proportionate and meaningful, we believe clearer thresholds are required to identify in what circumstances a HRE is required. Otherwise, there is a risk that the HRE could lead to a tokenistic exercise approach which is significantly diluted in impact.

Without a clearer process, we believe there is a risk of an abdication of responsibility where, because everyone is thought to be responsible, in reality no one is. Additionally, the requirement to complete an HRE without clearly demarcated roles and responsibilities for assessment and review could mean the process loses its effectiveness and meaning. There are also practical challenges in recording, storing, reviewing and sharing across different IT systems. This could result in multiple HRE containing outdated information.

SCLD believes there is an important role for a revised and tightened HRE which is better defined, more rigorous and accompanied by clearer roles and responsibilities for professionals.

If revised in this way, we believe HRE can play a critical role in ensuring professional decision making is necessary and proportionate to protecting an individual's full range of rights. We see a particular role for HRE where a potential intervention is contrary to the will and preference of an individual or that expressed in a statement of rights, will and preference or where there is disagreement between professionals about the requirement for an intervention. The basis for such an intervention would then be justified on an assessment of an

individual's competing rights and their expressed will and preference through the HRE process.

Summary of Key Points:

- **18.** In order to be proportionate and meaningful clearer thresholds are required to identify in what circumstances a HRE is required.
- **19.** Without a clearer process and identifiable roles and responsibilities there is a risk that no one take responsibility for the HRE process.
- **20.** The wide application of HRE responsibilities entails practical challenges in recording, storing, reviewing and sharing HRE information.
- **21.**There is an important role for a revised and tightened HRE which is better defined, more rigorous and accompanied by clearer roles and responsibilities for professionals.
- **22.**HRE can play a critical role in assessing the requirement for an intervention on the basis of an individual's competing rights and their expressed will and preference.

Section 6. Autonomous decision making test:

What are your views on the current capacity and SIDMA tests?

SCLD has concerns about how capacity and 'significantly impaired decision-making ability' (SIDMA) are assessed by clinicians and practitioners and a lack of clear guidance for practitioners on how to assess SIDMA⁴⁶. The current criteria for SIDMA

⁴⁶ <u>SCLD response to Stage 1 of SMHLR (2020)</u>

are not defined in law and the Code of Practice explains that whilst the concept is formally considered to be separate to that of "incapacity", in practice it seems similar factors are considered as when assessing incapacity⁴⁷.

People First (Scotland) have stated that "there is no agreed, reliable and accepted method of assessing capacity in Scotland and "...it remains an entirely subjective and unscientific process based mainly on prejudicial assumptions about intellectual impairment"⁴⁸.

Furthermore, a report published by the Mental Welfare Commission has noted that 'whilst a variety of people are consulted through Mental Health Tribunal processes including psychiatrists, psychologists, carers and specialist lawyers, a normative standard on capacity assessment is lacking in Scotland'⁴⁹.

The UNCRPD committee General Comment 1 on Article 12 rights states that '*Mental* capacity is not, as is commonly presented, an objective, scientific and naturally occurring phenomenon. Mental capacity is contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity'⁵⁰.

Furthermore, it adds that capacity assessments deny 'the right to equal recognition before the law...a person's disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the

⁴⁹ Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health and Capacity Law: the Case for Reform (2017)

⁵⁰ <u>UNCRPD General Comment No.1 (2014)</u>

⁴⁷ <u>Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health</u> <u>and Capacity Law: the Case for Reform (2017)</u>

⁴⁸ People First (2020) Response to SMHLR Capacity Assessing Survey

*exercise of legal capacity*⁵¹. Therefore, SCLD has significant concerns about the use of capacity assessments and the SIDMA test which together with the concept of *'mental disorder'* currently underpin the diagnostic threshold for compulsory interventions such as detention and involuntary treatment. We believe the consequences of this denial of autonomy, based even in part on a characteristic such as learning disability, is discriminatory.

Summary of Key Points:

- **23.**Significant concerns around a lack of clear guidance on how to assess SIDMA and lack of a normative standard on capacity assessment.
- **24.** In line with the UNCRPD, we believe compulsory interventions and denial of autonomy, on the basis of learning disability and capacity assessments is discriminatory.

What are your views on the concept of the test of autonomous decision making, distinct from a capacity or SIDMA test?

People First (Scotland) have raised significant concerns about the ADM test and state that: "*for people with a lifelong intellectual impairment when there is no severe mental illness…we see no difference between an ADM and a test of capacity or a SIDMA"* (Significantly impaired decision making assessment)⁵².

Whilst we welcome the proposals attempt to increase the compliance of Scots' law with both ECHR and UNCRPD by seeking to shift the focus of the criteria from a diagnosis of *'mental disorder'*, we share some of the concerns People First (Scotland)

⁵¹ UNCRPD General Comment No.1 (2014)

⁵² People First submission to SMHLR (2022)

have about that the Autonomous Decision Making test. In many respects, we believe it is a capacity test in another guise.

The proposals outline the concept of a ADM test which is based whether the person can make an autonomous decision in the context of the SDM and HRE supportive frameworks. In this model, any potential restrictions on individuals would start from the same basis of looking at a person's need for support in making decisions. Significantly, it would be the impairment of autonomous decision making that is used to justify involuntary treatment, not any specific diagnosis and this therefore may apply potentially to anyone.

SCLD has concerns, however, around the inclusion of what the proposals call 'controlling influences' which may be legitimately judged to present a barrier, or barriers, to an individual's autonomous decision making. These include:

- The impact of a person's illness or condition
- Crisis

The proposals state that in European human rights law these factors *'may in limited circumstances provide justification for detention, involuntary treatment or other decisions without consent*⁵³. SCLD does not believe that a characteristic such as learning disability or 'crisis' such as carer or placement breakdown should ever legitimise detention or involuntary treatment. Article 5 of the EHRC⁵⁴ on the Right to liberty and security is clear that:

Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

⁵³ <u>SMHLR consultation March 2022</u>

⁵⁴ EHRC Article 5, Right to Liberty and Security

(e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants.

We agree that priority or 'special regard' should be given to a person's will and preferences either as directly expressed or via an advance statement of rights, will and preferences and that this should include:

- Making all efforts to best understand the person's will and preferences
- Giving effect to these
- Only limiting the person's rights if this will demonstrably lead to more respect, protection, and fulfilment of the person's rights overall, and
- Only limiting rights to the extent required to achieve these protections.

This is in line with the Rome Review that recommended that, with respect to people with learning disabilities professionals should act to put each person's will and preferences into effect and that it should become rare for professionals not to do this. If a professional thought that the person's will and preference for support, care or treatment would harm the person's rights overall, then the professional might be able to justify not following the person's will and preference. This justification would have to be made in terms of the person's human rights, and would have to show that the professional's decision was proportionate in that it gave benefit to the person's human rights overall⁵⁵.

In view of this, SCLD believes that the ultimate arbitration should not be whether someone is able to make an autonomous decision but rather whether contravening an individual's will and preferences is a necessary and proportionate means of protecting the full range of someone's rights and freedoms.

⁵⁵ <u>The Independent Review of Learning Disability and Autism in the Mental Health Act (2019): Final</u> <u>Report</u>

The test for this should be the Human Rights Enablement assessment process. However, as stated, we believe the proposed HRE needs revised and tightened to be more rigorous and defined alongside clear roles and responsibilities for professionals. If this is achieved, we believe a HRE should be required before any intervention that overrides the will and preference of any individual is permissible. The basis for such an intervention should be justified on an assessment of an individual's competing rights and their expressed will and preference through the HRE process.

Furthermore, any statement of rights, will and preference would have to be directly and wholly addressed in any professional decision making that might limit the person's human rights. There should be a right to challenge any professional decision that does not respect a person's will and preferences, and which may not be proportionate for their human rights. This should also be accompanied by a right in law to notify the appropriate scrutiny bodies when any statement of rights, will and preferences is not complied with, in addition to duties on professionals to report this.

Summary of Key Points

- The attempt to shift the focus of the criteria from a diagnosis of *'mental disorder'* is welcome but we are concerned that the ADM remains a capacity test in another guise
- 2. We are concerned around the inclusion of *'controlling influences'* which may be judged to present a barrier to an individual's autonomous decision making
- 3. The ultimate arbitration should not be whether someone is able to make an autonomous decision but rather whether contravening an individual's will and preferences is a necessary and proportionate means of protecting the full range of someone's rights and freedoms

- 4. The basis for such an intervention should be justified on an assessment of an individual's competing rights and their expressed will and preference through the HRE process
- **5.** Any statement of rights, will and preference must be directly and wholly addressed in any professional decision making that might limit the person's human rights
- 6. There should be a right to challenge any professional decision that does not respect a person's will and preferences, and which may not be proportionate for their human rights
- 7. There should be a right to notify the appropriate scrutiny bodies when any statement of rights, will and preferences is not complied with, in addition to duties on professionals to report this

Section 7. Reduction of coercion:

What are your views on how the Review understands coercion?

What do you think about the Review's proposed approach to reducing coercion, including reducing the use of involuntary treatment?

At our engagement event on the SMHLR proposals, some members of Restraint Reduction Scotland reflected that this section unhelpfully mixes up coercion with compulsion. It was emphasised that while law and policy are important, resources are essential in bringing about the culture change that is required to successfully challenge coercive practice. At the same time the need for greater safeguards in law was recognised and it was felt that the safeguards in the 2003 Act are significantly stronger than those in the AWI Act. Lack of scrutiny with regard to care homes was raised as a particular area of concern. Addressing the lack of consistency of across the legal frameworks was highlighted as essential in the developing greater protection of human rights compliance and compliance with international human rights. SCLD views coercion as a systemic issue and we welcome the SMHLR's approach to looking at all involuntary support, care and treatment. The proposals state that:

Coercion is generally understood to involve force or the possibility of force. Detention and compulsory treatment under the 2003 Act, for example, is inherently coercive. However, coercion is not only about detention, restraint and seclusion in their various forms. It also includes other restrictive practices such as surveillance without informed consent, interference with private communication, and restrictions on social relationships.

Coercion, therefore, describes a very broad range of actions and we believe that in defining coercion for the purposes of law, policy and practice it may be important to make a distinction between compulsion in terms of interventions which are authorised by the 2003 Act or the AWI Act, and wider restrictive practices including restraint, seclusion, blanket restrictions and de-facto detention without proper legal process.

All forms of coercion can be inherently distressing and traumatising, and while we accept that compulsion can be necessary and proportionate as part of promoting and protecting all of a person's relevant human rights, in our view wider restrictive practice and their misuse should be eliminated.

We broadly support the proposals approach to reducing coercion in services though a focus on the following elements:

- Sense of belonging, connection and trust in society
- Support, services and approaches which reduce the use of coercion
- Stronger safeguards when compulsion is authorised
- Monitoring and scrutiny

We believe that legislative reform can help drive changes which can reduce the use of restrictive practices including changes to physical environments, better resources,
improved support, supervision, training and leadership for staff, improved recording, monitoring and reporting and changing attitudes and culture.

In this process, we believe there is significant learning to be gained from the work, expertise and learning of Restraint Reduction Scotland (RRS).

RRS was established in April 2020 in recognition of the fact that the use of restrictive practices with people who have been identified as vulnerable in Scotland, including children, young people, adults and older adults, is a significant concern.

The aim of Restraint Reduction Scotland (RRS) is to eliminate the misuse of restrictive practices, including physical, chemical, environmental and mechanical restraints, and seclusion. This is to ensure that where these are used, they are done so safely, with respect for people's human rights and in a culture of openness and transparency. RRS also exists to promote the use of positive alternative approaches to the use of restrictive practice. RSS has three core areas of focus⁵⁶:

• Leadership and Culture Change

For systemic practice change aspired to above to occur, culture change is required. This culture change must include engaged and informed leadership by senior management and significant training and development work focusing on how staff interact with people, what skills they have, and recovery and transformation principles. Furthermore, the voice of people with lived experience needs to be central to any culture change agenda and approach.

• Workforce Development, Prevention and Practice Leadership

This needs to be about more than just training and include culture change and leadership. It is also critical to ensure that the voice of people with lived experience

⁵⁶ <u>Restraint Reduction Scotland, Vision and Direction (2021)</u>

is represented in training, particularly with a focus on trauma. There is a need to train staff in alternatives to restrictive practices recognising that if restraint is all that staff are aware of, that is what they will use. Follow-up training needs to be developed with person-specific action plans to reduce the use of restrictive practices. Furthermore, there is a need to focus on positive and preventative methods such as trauma informed practice, inclusive communication and positive behaviour support. Training must be tiered for different levels, modular, and with opportunities to apply training to practice. There must be ongoing support to staff to enable them to change their behaviour.

• Monitoring & Data Collection

There is a need for improved governance and oversight of data to support better collection and on-going monitoring of information and to ensure that we can identify the scale and scope of the use of restrictive practices in Scotland. This should also support the development of a learning culture where staff are encouraged to reflect on their practice and suggest and implement changes. It must also include learning from incidents and post incident review and reflection. Evidencing personal stories from those with lived experience is also critical in demonstrating the impact of restrictive practices on individuals and supporting the development of alternative practices.

Summary of Key Points:

- **25.**There is a requirement for greater safeguards in law particularly in relation to the 2003 Act.
- **26.** All forms of coercion can be inherently distressing and traumatising, and while we accept that compulsion can be necessary and proportionate as part of promoting and protecting all of a person's relevant human rights, in our view wider restrictive practices and their misuse should be eliminated.
- 27. We broadly support the proposal's approach to reducing coercion in services and believe there is significant learning to be gained from the work, expertise and learning of Restraint Reduction Scotland (RRS) on Leadership and Culture Change; Workforce Development, Prevention and Practice Leadership; and Monitoring & Data Collection.

Section 8. Accountability:

What do you think about our proposals to give the Mental Health Tribunal increased powers to order that specific care and / or support to be provided for a person? What are your thoughts on collective advocacy groups raising court actions? Do you have any suggestions to make the scrutiny landscape for mental health services more effective? What do you think about the ways in which we think the role of the Mental Welfare

Commission should be extended? Do you have other ideas?

SCLD is supportive of several key initial proposals in relation to the remit of the Mental Welfare Commission outlined on page 130 of the consultation document. We are supportive of the core remit to safeguard and promote human rights covered by mental health, increasing work in community settings and power to initiate legal proceedings in relation to mental health and capacity law. Moreover, SCLD supports increasing the role of independent advocacy and strengthening the role of collective advocacy with a view to raising court actions.

However, as stated throughout this response, SCLD is deeply concerned about the failure of this review to take account of the Rome Review's recommendations to remove learning disability from *'mental disorder'*. The failure to disentangle learning disability from existing mental health legislation means that proposals do not account for or fully explore the potential of a new multi-institutional approach to accountability and justice being proposed as part of the new Human Rights Bill for

Scotland and the potential role a Learning Disability, Autism and Neurodiversity Commissioner can play in this.

A potential example of how this approach might work is that the Mental Health Tribunal for Scotland should have strengthened powers with regard to *'recorded matters'* to help ensure a person has the support in place to allow a detention to end. However, when this becomes an issue of delayed discharge relating to a person with a learning disability, SCLD believes there will be an additional role for the proposed Learning Disability, Autism and Neurodiversity Commission/er to enforce the recommendations of the Coming Home Implementation Report⁵⁷.

While SCLD supports the existing bodies retaining a scrutiny role pertaining to mental health support and treatment we are concerned that when no agreement has been reached on removing learning disability from *'mental disorder'* that proposals have been made regarding extending powers to issues such as employment, education, housing and social connections (p.129). SCLD sees this as an overstep of the review given its failure to listen to the views of people with learning disabilities expressed in the Rome Review. Instead, we believe conversations on the developing multi-institutional scrutiny landscape sits firmly within the new Human Rights Bill for Scotland.

Summary of Key Points:

- 28. Support for the core remit of the Mental Welfare Commission outlined on page 130 of the consultation document
- 29. Exploration of further scrutiny powers pertaining to rights such as ISCER and the UNCRPD to happen alongside the development of a new Human Rights Bill for Scotland

⁵⁷ <u>Scottish Government (2022)</u>

Section 9. Children and Young People:

Do you think the current 2003 Act principle for Children is still needed? Should it be replaced by a wider principle of respecting all the rights of the child under the UNCRC in any intervention – or something else? What do you think about having a statutory duty on Scottish Ministers and health and care agencies to provide for children the minimum standards needed to secure the human rights set out in international treaties such as the UNCRC?

SCLD welcomes the proposal that Section 2 of the 2003 Act be amended to ensure that all the rights of the child under the UNCRC should be respected in any intervention. With regard to children and young people with learning disabilities we would also welcome compliance where appropriate with relevant articles of the UNCRPD. To ensure these principles are enforceable and monitored we would recommend that exploration is undertaken on how this may be monitored as part of the Children's Scheme as legislated for in Part 3 of the UNCRC Incorporation (Scotland) Bill⁵⁸.

SCLD believes it is appropriate for a statutory duty to meet a minimum core of obligations necessary to secure the right to the highest attainable standard of mental health for children and young people which should be both attributable and enforceable. However, meeting a minimum core should not be where aspirations

⁵⁸ <u>UNCRC Incorporation (Scotland) Bill</u> (2021)

end. Therefore, SCLD would welcome an additional commitment to continue progressive realisation of the rights of children and young people accessing mental health services in line with Article 24 of the UNCRC. As stated, Part 3 of the UNCRC Incorporation Bill (Scotland) offers a unique opportunity to report on children's rights which are most at risk of not being realised and ensuring this is utilised will be paramount.

What are your thoughts on how supported decision making, human rights enablement and the autonomous decision making test, in Chapters 3,5 and 6 might apply to children and young people? What do you think about our proposals on accountability? What are your views on autism, learning disability and neurodiversity and the possible law reforms for children and young people?

In responding to the question on the role of supported decision making, human rights enablement and autonomous decision making test, SCLD asks that the Review reflects back on our comments in sections 3, 5 and 6.

SCLD would welcome an exploration of a supported decision-making approach which is specific to working with children and young people. In doing this SCLD asks the review considers how this processes can support Article 12 of the UNCRC⁵⁹ and the UNCRC General Comment 12⁶⁰ which outlines that in decisions regarding health care, children should be included in a way that is consistent with evolving capacities. For disabled children and young people, including children and young

 ⁵⁹ <u>Article 12 UNCRC (1989)</u>
⁶⁰ <u>UNCRC General Comment No. 12 (2009)</u>

people with learning disabilities, this includes the provision of accessible information to support them in decision making.

In developing a process which supports children and young people to make their views heard in relation to mental health support and treatment further consideration should also be given to Articles 25 and 37 of the UNCRC and how supported decision making can support realisation of these rights. To help achieve this there will be significant learnings to be gained from the children's sector in Scotland given their considerable experience in ensuring the voices of children and young people are heard and taken into account. Therefore, SCLD asks that the Review team engages with the children's sector in Scotland on this issue and takes into consideration evidence based approaches which can support the realisation of UNCRC article 12 rights such as the Lundy Model of Child Participation⁶¹

As discussed, SCLD's position on the inappropriateness of the inclusion of learning disability within the Mental Health Act, extends to children and young people. Instead of the current approach we would advocate for recommendations made by Rome Review relating to co-ordinated support plans and their implementation are realised through alternate legislation. At this time SCLD does not believe the Mental Health Act is the appropriate place to seek to put into effect measures to support realising Article 23⁶² of the UNCRC. Instead, alternative provisions such as the Learning Disability, Autism and Neurodiversity Bill may provide a more suitable asset-based approach to support the realisation of such positive rights. With regards to accountability there should be a role for both a Learning Disability. Autism and Neurodiversity Commissioner and the existing Children and Young People's Commissioner for Scotland in ensuring the implementation of these positive rights.

⁶¹ <u>Queens University Belfast</u> ⁶² <u>Article 23 UNCRC (1989)</u>

SCLD believes the ongoing development of both the incorporation of the UNCRPD in the Human Rights Bill for Scotland, UNCRC incorporation and the proposed Learning Disability, Autism and Neurodiversity Bill presents us with a complex legislative picture with a number of potential scrutiny bodies. Given this SCLD would seek to ensure future human rights legislation supports and enhances realisation of Article 23 of the UNCRC and does not further complicate this issue.

Do you have views on the idea of moving mental health law for children to connect it with other law for children, to apply across education and social care?

In line with ensuring UNCRC and UNCRPD rights are realised for children and young people with learning disabilities we believe it may be sensible to align, not integrate, the mental health, education and social care laws impacting children. Again, SCLD would see the UNCRC Incorporation Bill as the best starting place for this process ensuring both duties and accountability.

At SCLD's SMHLR consultation events we heard a mixture of views on this proposal. Parents of children and young people with learning disabilities welcomed the idea of a *"consistency of approach" and an "easier pathway for families and professionals to follow".* However, we also heard concerns from legal professionals who expressed that there was a risk specialism would be lost in a more universalist approach. Given this, and a lack of clarity on the proposal within the review document on what this proposal would mean in practice, SCLD believes further detailed stakeholder engagement is required on this issue with the Scottish children's and legal sector to ensure the rights of children and young people in Scotland are best realised.

Summary of Key Points:

- **30.** Replace 2003 principle for children to a commitment respecting all the rights of the child in any interventions.
- **31.** Support for a statutory duty for Scottish Ministers and Health Care agencies to meet minimum core obligations in relation to UNCRC with proposed added commitment to continue progressive realisation of these rights beyond a minimum standard.
- **32.**Utilise the UNCRC Children's Scheme as a reporting tool for monitoring respecting the rights of a child in any intervention and statutory duties for Scottish Minister and Health Care Agencies.
- **33.**Explore the potential supported decision making approach to working with children and young people accessing mental health support and treatment drawing from existing expertise in the Scottish Children's Sector and evidence based models of participation.
- **34.** Explore alternate legislation to ensure disabled children including children and young people with learning disabilities rights to coordinated support plans and their implementation with a view to supporting the realisation of Article 23 of the UNCRC.
- **35.**Conduct focused stakeholder engagement with the children's sector on the issue of integrating child law and mental health law.

Section 10. Adults with Incapacity proposals:

What are your views on the new model?

We broadly support the proposed 'decision making framework' encompassing: decision supporter, power of attorney and decision-making representative. In our view this represents a departure from existing substitute decision-making structures and provides greater scope for support for decision making and decisions based on the will and preference of the adult, or the best interpretation of these. People with learning disabilities have also told us that some of the language used in the current legislation, including the term 'guardianship' feels stigmatising. SCLD has stated previously⁶³ that the term 'guardian' has become archaic and is loaded with many negative and paternalistic connotations. We therefore welcome the proposal to cease use of the term 'guardianship' and support the use of the terms 'decision supporter' and 'decision-making representative'. In addition, we propose that the name of the legislation itself should be changed to focus on 'capacity' rather than 'incapacity'. We believe this change in terminology would help shift the emphasis towards legislation which is supportive rather than restrictive.

More substantively, we particularly support the provisions within the proposals for the role of decision supporter. In our view, the creation of this role, which gives clear authority to support individual decision-making being legally recognised is critical in supporting people with learning disabilities to exercise their Article 12 rights in the CRPD.⁶⁴ This role has much in common with the 'registered decisionmaking supporter' proposed by People First (Scotland)⁶⁵ and the 'Decision-Making Assistant' in the Irish Assisted Decision-Making (Capacity) Act 2015. There may by learning from this around the implementation, in particular the appointment process based on a Decision-Making Assistance Agreement⁶⁶.

With respect to the decision-making representative, we recognise the need for structures which permit authorisation of decision making on behalf of someone where they face barriers to doing so themselves, even with significant support. However, we believe that all the measures within the legislation should be constructed as a form of support, ranging from light touch assistance to intensive

⁶³ <u>SCLD response to AWI Act proposals for reform consultation (2018)</u>

⁶⁴ UNCRPD (2007)

⁶⁵ People First (2017) Framework for Supported Decision Making

⁶⁶ Irish Assisted Decision-Making (Capacity) Act 2015

support as far as is possible. In some circumstances this could termed "100% support", based on the "best interpretation of will and preferences"⁶⁷. We believe conceiving of it in this way, as a form of support, is critical in moving away from the idea that some identifiable line exists beyond which it is legitimate to remove a person's legal capacity.

Summary of Key Points:

- 36. There is a need for reformed capacity legislation which is supportive rather than restrictive encompassing a new decision-making framework and accompanied by revised terminology.
- 37. Regarding implementation, there may be learning from the People First (Scotland) Supported Decision Making Framework and Irish Assisted Decision-Making (Capacity) Act 2015.
- 38. The new framework must be adequately resourced at a national and local level.

Will the proposed change address the issues currently experienced with guardianship?

At present, the Adults with Incapacity (AWI) Act requires the least restrictive option; however, this is often not reflected in individual experience. People with learning disabilities who took part in SCLD's recent UPR consultation events told us that guardianship orders entail a serious restriction on their choice, autonomy, and privacy⁶⁸. This is concerning given that people with learning disabilities represent 45% of all welfare guardian orders under the AWI Act⁶⁹. People First (Scotland)

⁶⁷ UNCRPD General Comment No.1 (2014)

⁶⁸ SCLD UPR submission (2022) – (available on request)

⁶⁹ <u>Mental Welfare Commission (2018)</u>

believe that all forms of Guardianship should be scrapped and that capacity law needs to be wholly rewritten to remove substitute decision-making and guarantee the right to legal capacity alongside support for decision-making to make the rights, will and preference of individuals paramount⁷⁰.

There are also serious concerns about the lack of automatic, periodic judicial scrutiny of guardianship in relation to indefinite orders, which apply to 5% of people with learning disabilities⁷¹. Article 12(4) CRPD requires regular review of measures relating to the exercise of legal capacity by a competent, independent, and impartial authority or judicial body⁷². Article 8 ECHR requires that interferences must be in accordance with the law, which must guarantee proper safeguards against arbitrariness⁷³.

At the same time, we are aware of the challenges of the current guardianship application process which is cumbersome, characterised by delays, costly and lacking in flexibility. We recognise the desire to speed this process up and note the proposal for the appointment of a judicially appointed decision-making representative by 'pro-forma application'. However, we believe it is critical that significant care is taken to ensure the proposed reforms do not in any way risk diluting existing safeguards and inadvertently permitting greater interference with the human rights of people with learning disabilities who may be subject to formal measures under capacity law.

We would like the reformed legislation not only accompanied by a Code of Practice but also underpinned by a robust set of revised principles within the Act which are rights based and have duties and scrutiny attached to them. We believe, this should

⁷⁰ People First Alternative Summary on the Scottish Mental Health Law Review

⁷¹ <u>Mental Welfare Commission (2018)</u>

⁷² <u>UNCRPD (2007)</u>

⁷³ <u>European Convention on Human Rights</u>

include the introduction of a principle which safeguards individuals' rights by ensuring that an adult's will and preferences are only contravened in actions under the Act if it is shown to be a necessary and proportionate means of protecting the full range of the person's rights and freedoms. There should also be an attributable and enforceable duty to demonstrate the provision of support for decision making alongside clear guidance about who bears the responsibility for this.

We agree that situations where an individual is appointed without the consent of the adult to take decisions should require judicial oversight. We also believe there should be a requirement in every case that the judicial authority must meet the adult to whom the application relates. In addition to this, it is critical that people with learning disabilities are supported to be aware of their rights and are offered the necessary support to fully participate in AWI processes. This should include obligations to involve individuals at the earliest stage and determine the appropriate support with a view to maximising people with learning disabilities' autonomy and reducing the need for formal measures.

It is critical to have clear structures for reporting of concerns about all matters relating to AWI. We see a role for the Office of the Public Guardian (OPG) to register, oversee and support the process and to investigate any complaint of conflict of interest or undue influence. Additionally, we believe supervision of the decision making representative is an essential safeguard. This must be well resourced and there may be merit in a model of joint working between the OPG, MWC and local authorities. However, the potential for conflicts of interest from a local authority perspective in determining whether supervision is necessary, must be borne in mind.

Summary of Key Points:

- 39. Extreme care must be taken to ensure the proposed reforms do not in any way dilute existing safeguards and inadvertently permit greater interference with human rights.
- 40. Reformed legislation should be underpinned by a robust set of revised principles within the Act which are rights based and have duties and scrutiny attached to them.
- 41. People with learning disabilities require support, including funded independent advocacy and communication, to be aware of their rights and a view to maximising their participation and autonomy and reducing the need for formal measures.
- 42. The role of supervision is an essential safeguard which must be well resourced and designed to avoid conflict of interest.

What are your views generally on POA and the recommendations we are proposing?

SCLD is of the view that the proposals around POA do not go far enough. In addition to more sufficient guidance for attorneys and clarity around investigatory responsibilities, we believe there is a need to look again at the system for granting POA and access to judicial oversight. As previously stated⁷⁴, we have concerns around the lack of safeguards that POA provides to ensure individuals are not subject to restrictions on their liberty when the authority to create such restrictions rests solely in a POA. We believe there is a requirement for additional safeguards including access to a judicial procedure capable of determining the lawfulness of an

⁷⁴ <u>SCLD response to AWI Act proposals for reform consultation (2018)</u>

individual's detention. Additionally, welfare powers of attorney are not subject to review and supervision in the way guardianship orders are. We do not believe the proposals around supervision are sufficient. In our view, regular reviews should be an automatic requirement of power of attorney.

43. Stronger safeguards are required for POA including access to a judicial procedure capable of determining the lawfulness of an individual's detention.

44. Regular reviews should be an automatic requirement of power of attorney.

What are you views on the proposals?

What are your thoughts on the provisions within s47(7) on the use within the AWI

Act of force and detention and the relationship with the 2003 Act?

At present, section 47 certificates can effectively exclude the adult's views if they are perceived to lack capacity. We believe any procedure must begin with specific steps to support the adult to make a decision and exercise their legal capacity. While there is currently a requirement to seek the views of guardians and attorneys, there is no guidance as to how an individual's objection to treatment should be dealt with⁷⁵. In line with earlier comments there must be greater emphasis on establishing the will and preference of the adult and working towards their consent, in the first instance.

⁷⁵ <u>Adults with Incapacity Act (Scotland) 2000</u>

We agree that there should be a streamlined process whereby an individual can challenge a decision to grant a section 47 certificate, or a treatment authorised under that certificate. In addition, we propose a short appeal period should be allowed to elapse before treatment can take place. Access to justice is an area where people with learning disabilities face significant barriers and we believe increased support and greater safeguards are required for individuals who may find it difficult to access and instruct an appeal to the sheriff.

Section 47 (7) provides that the treatment authority does not authorise 'the use of force and detention, unless it is immediately necessary and so long as is necessary in the circumstances' or 'placing an adult in a hospital for treatment against his will'. We have concerns around the lack of specification as to 'so long as is necessary' and that this can often cover multiple interventions over a period.

It is our view that separate safeguards are required to address the question of detention and the question of treatment. The ECtHR has made clear that authorisation to administer non-consensual treatment does not automatically follow from authorisation to detain, instead requiring separate substantive and procedural safeguards⁷⁶. We believe that the reverse also applies with the appropriate safeguards alongside clear and specific procedures.

Finally, SCLD recognises that there are significant issues around training, guidance and supervision concerning Section 47. We believe revised guidance on supporting decision making and reviewed training for those who grant section 47 certificates must address the issue of covert use of antipsychotic medication which is regularly prescribed under section 47. SCLD has previously raised our concerns about evidence that antipsychotic medications are being used to manage 'problem

⁷⁶ <u>FS_Detention_mental_health_ENG (coe.int)</u>

behaviours'⁷⁷ with widespread use of 'off-label prescribing' of these medications for people with learning disabilities⁷⁸ on a long-term basis despite significant side effects which pre-dispose to premature mortality⁷⁹ and with no reliable evidence of effectiveness beyond sedation.⁸⁰ We believe there is a need to think very carefully about any extension of the range of healthcare professionals who can issue a section 47 certificate that could risk widening the scope for restricting the adult's legal capacity and permitting non-consensual interventions.

Summary of Key Points:

- **45.** Provision should be made for a short appeal period to elapse before treatment can take place.
- 46. Increased support and greater safeguards for individuals with individual and others who may find it difficult to access and instruct an appeal process should be introduced.
- 47. Separate safeguards are required to address the question of detention and the question of treatment, with clear and specific procedures for each.
- 48. Revised guidance on decision support and reviewed training for those who grant section 47 certificates must address the issue of covert use of antipsychotic medication.
- **49.** Caution is required around extension of the range of professionals who can issue a section **47** certificate that could risk widening the scope of non-consensual interventions.

⁷⁷ <u>SCLD submission to Stage 1 of SMHLR</u>

⁷⁸ <u>SLDO (2017) 10 years of anti-psychotic prescribing in Scotland</u>

⁷⁹ Tyrer, P & Cooper, S (2014) Drug treatments in people with intellectual disability and challenging behaviour (2014)

⁸⁰ SLDO (2017) 10 years of anti-psychotic prescribing in Scotland

Section 11. Deprivation of Liberty:

What are your views on the deprivation of Liberty proposals?

SCLD has previously expressed concerns about the use of section 13ZA to transfer people to care homes⁸¹. In our view, this practice lacks sufficient safeguards against arbitrary detention and substitute decision-making. Additionally, in considering deprivation of liberty, we believe it is important to pay attention not only to the physical setting but also to the appropriateness of the care itself. The nature of care arrangements has potential to restrict a range of rights and engage a deprivation of liberty in a broad sense.

The Cheshire West ruling by the UK Supreme Court in 2014⁸² and the findings of the Scottish Law Commission's report on Adults with Incapacity⁸³ highlighted the need for further legal and procedural safeguards to protect those considered unable to consent to a deprivation of liberty. These concerns were heightened during the pandemic with research⁸⁴ finding that people had been moved during this time without the protection of legal authority and expressing significant concern that these cases may also constitute Article 5 deprivation of liberty and a breach of the European Convention on Human Rights (ECHR)⁸⁵.

Preventing an individual from leaving hospital may also give rise to a deprivation of liberty. Living in a hospital setting without clinical need or being placed out of area

⁸¹ <u>SCLD response to AWI Act proposals for reform consultation (2018)</u>

⁸² Deprivation of Liberty Advice Notes, Mental Welfare Commission (2015)

⁸³ <u>Report on Adults with Incapacity, Scottish Law Commission (2014)</u>

⁸⁴ Mental Welfare Commission (2021)

⁸⁵ European Convention of Human Rights

without choice is an excessive restriction on liberty and the right to home life. '*The Coming Home report*' showed 67 people with learning disabilities and complex needs were subject to a delayed discharge, a fifth for more than 10 years, and also identified 705 people living in Out of Area Placements (OAPs), far from their family and local community⁸⁶.

SCLD recognises the challenges around ensuring a lawful process to authorise deprivations of liberty. In the first instance, we believe it is critical that every effort is made through supported decision making structures to maximise an individual's autonomy and seek informed consent to ultimately avoid a deprivation of liberty.

Furthermore, where an individual with support has expressed a will and preference to remain in their current living arrangement, even where this could be perceived to constitute a deprivation of liberty, we believe this should provide valid consent for the purposes of Article 5 in the EHCR. In our view, provision should be made to detail the obligations on those proposing and/or providing the care and living arrangements and to evidence the specific steps that have been taken to validate consent. This process requires sufficient oversight.

In circumstances where, even with significant support, it has not been possible to establish the will and preference of an individual and where their care and wellbeing are subject to continuous supervision and control and not free to leave, we believe this must be subject to a judicial process. A court or tribunal should then grant the necessary power to the decision making representative.

As discussed earlier, we have concerns around the lack of safeguards that POA currently offers to ensure individuals are not subject to restrictions on their liberty

⁸⁶ <u>Scottish Government (2018)</u>

and believe there is a requirement for a judicial procedure capable of determining the lawfulness of an individual's detention.

We do not believe it should be possible for an individual to consent to their own deprivation of liberty, where they have not been able to make an autonomous decision with support.

Summary of Key Points:

- 50. The need for a requirement for obligations on those proposing the care arrangements to demonstrate the steps they have taken to maximise autonomy accompanied by necessary oversight for this process.
- **51.** The granting of power to the decision-making representative must be subject to a judicial process.
- 52. Additional safeguards are required for POA including access to a judicial procedure capable of determining the lawfulness of an individual's detention.
- 53. Where an individual has not been able to make an autonomous decision with support, it should not be possible for an individual to consent to their own deprivation of liberty.

Section 12. Mental Disorder:

What are your views comments, suggestions or thoughts around mental disorder?

In our submission to the Rome Review, SCLD argued that the inclusion of learning disability in the term *'mental disorder'* as defined by mental health law serves to perpetuate the marginalisation of people with learning disabilities and risks

legitimatising the restriction of rights including detention and non-consensual treatment on the basis of disability.⁸⁷

Defined as having a *'mental disorder'*, people with learning disabilities have been considered to have a medical condition, that necessarily requires medical care and treatment⁸⁸. SCLD believes that defining learning disability in this way obscures societal structures and practices that deny people with learning disabilities access to active participation in society and the full enjoyment of their rights.

As discussed throughout this response SCLD do not believe that the automatic inclusion of people with learning disability within the term mental disorder and associated legislative framework, is compliant with human rights either in the ECHR, the UNCRPD, ICESCR or UNCRC. Furthermore, we do not believe that labelling all people with learning disabilities as '*disordered*' is consistent with respect for dignity and the inherent worth of an individual which constitutes one of the four core principles proposed by the SMHLR.

The SMHLR proposals recognise that people are uncomfortable with the term *'mental disorder'*, that it is the language of deficit, that the inclusion of learning disability within this definition is regarded by many people with a learning disability as deficit based.

People First (Scotland) state that⁸⁹:

"We remain of the view that the term mental disorder is not offensive or insulting to us as people with intellectual impairment, it is simply inaccurate and misleading. We agree that the Mental Health Act was designed for people with mental illness

⁸⁷ SCLD submission to IRMHA Stage 3 (2019)

⁸⁸ (2001) Chappell, A British Journal of Learning Disabilities. Making connections: the relevance of the social model of disability for people with learning difficulties

⁸⁹ People First submission to SMHLR (2022)

and that it has been unhelpful. We have been stuck in a system which was never designed to meet our needs.

It has also been instrumental in our discriminatory oppression, particularly in respect of our Article 5 (ECHR) rights to liberty and security of person and our Article 12 (UNCRPD) rights to equal recognition before the law and to recognition of our autonomy. We struggle to understand why the Rome Review recommendation for separate legislation for people with a learning disability to achieve equity and human rights has not been accepted by the SMHLR."

SCLD shares these views and concerns. We are extremely disappointed, therefore, that these proposals have not reached a decision on whether to endorse the recommendation from the Rome Review that learning disability and autism should be removed from the definition of mental disorder. SCLD fully supports the Rome Review's proposed solution that learning disability and autism should be removed from the definition of *'mental disorder'* and that they should be defined in a separate law designed to provide support and equity in law.

Should there be a gateway to mental health and capacity law which reflects

a diagnostic criterion?

SCLD recognises that determining the appropriate gateway to mental health and capacity law is a complex issue. We believe that if someone with a learning disability has mental ill health that requires support, care and treatment over and above their lifelong disability, then mental health law should apply to them in the same way as for any other person.

However, we are also clear that transformative change is required to criteria not only to mental health law but also capacity law which also relies on the concept of mental disorder. We agree with the People First (Scotland) statement that *"we do not believe that the Review has taken seriously the argument that "mental disorder"*

needs to be unpicked and reconsidered in its entirety, not simply the name or label that is applied⁶⁰.

In our view, the gateway for compulsion under mental health and capacity law should be "de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis"⁹¹. We welcome the proposal's attempt to increase the compliance of Scots' law with both ECHR and UNCRPD by seeking to shift the focus from a diagnosis of *'mental disorder'*. As already stated, however, there are significant challenges in realising this non-discriminatory threshold for involuntary interventions which in our view are yet to be overcome.

We believe there may be merit in examining the proposals on Reforming the Mental Health Act in England and Wales which are clear that autism or a learning disability should not be considered to be mental disorders for the purposes of most powers under the act⁹². The White Paper proposes to allow for the detention of people with a learning disability and autistic people for assessment when their behaviour is so distressed that there is a substantial risk of significant harm to the person or to other people and a probable mental health cause to that behaviour that warrants assessment in hospital. Where the driver of this behaviour is not considered to be a mental health condition, for example it is due to an unmet support, social, emotional or physical need grounds for a detention under the MHA would no longer be justified and detention should cease.

⁹⁰ People First submission to SMHLR (2022)

⁹¹ Gurbai, Sandor and Martin, Wayne (2018) Is Involuntary Placement and Non-Consensual treatment Ever Compliant with UN Human Rights Standards?

⁹² Reforming the Mental Health Act

Summary of Key Points:

- 54. The inclusion of learning disability in the term *'mental disorder'* as defined by mental health law serves to perpetuate the marginalisation of people with learning disabilities and risks legitimatising the restriction of rights on the basis of disability.
- 55. Labelling all people with learning disabilities in this way is not compliant with a human rights approach or the core principles proposed by the SMHLR.
- 56.SCLD fully supports the Rome Review's proposed solution that learning disability and autism should be removed from the definition of *'mental disorder'* and that they should be defined in a separate law designed to provide support and equity in law.
- 57. Transformative change is required to criteria not only for health law but also capacity law which also relies on the concept of mental disorder.
- 58. The gateway for compulsion under mental health and capacity law should be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis.
- 59. There may be merit in examining the proposed changes in the White Paper on Reforming the Mental Health Act in England and Wales which are clear that autism or a learning disability should not be considered to be mental disorders for the purposes of most powers under the act.

Section 13. Fusion or aligned legislation:

What do you think about our suggestion of aligned legislation?

SCLD cautiously supports the suggestion by the SMHLR for a move towards aligned legislation. In the context of significant wider legislative reform we think this is more desirable than fused legislation. We see advantages in establishing, as far as possible, a common set of principles, safeguards and routes to remedy across the separate acts.

However, in this process of alignment and the transformative change that is required, we believe it is important to maintain an appropriate separation in the provisions within law for individuals who may fall within the remit of adult protection, adults with incapacity or mental health legislation. With respect to the AWI Act, we believe that the title of the legislation itself is changed to have a focus on support rather than on incapacity. We propose that something akin to the Irish legislation Assisted Decision-Making (Capacity) Act 2015 should be considered.

Furthermore, it is of critical importance that the existing Acts are suitably aligned and coherent with future legislative developments which are planned to further strengthen the architecture for human rights in Scotland. These include a Human Rights Bill⁹³, the UNCRC (Incorporation) (Scotland) Bill and a Learning Disability, Autism and Neurodiversity Bill.⁹⁴

As already stated, reformed mental health and capacity legislation must take account of the potential for a new multi-institutional approach to accountability and justice being proposed as part of the new Human Rights Bill for Scotland and the potential role a Learning Disability, Autism and Neurodiversity Commissioner can play in this.

The Mental Welfare Commission for Scotland and Centre for Mental Health and Capacity Law (Edinburgh Napier University) have highlighted the need for: *'a long-term programme of law reform, covering all forms of non-consensual decision-making...This should work towards a coherent and non-discriminatory legislative framework which reflects UNCRPD and ECHR requirements and gives effect to the rights, will and preferences of the individual*⁹⁵. In our view, this is the challenge

⁹³ Human Rights Bill

⁹⁴ Programme for Government 2021-22

⁹⁵ <u>Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health</u> <u>and Capacity Law: the Case for Reform (2017)</u>

that the SMHLR final recommendations must seek to address within the context of wider legislative developments designed to respect, protect and fulfil the human rights and well-being of people with learning disabilities and others in Scotland.

Summary of Key Points:

- **60.SCLD** cautiously supports a move towards aligned legislation and we see advantages in establishing, as far as possible, a common set of principles, safeguards and routes to remedy across the separate acts.
- 61. It is important to maintain an appropriate separation in the provisions within law for individuals who may fall within the remit of adult protection, adults with incapacity or mental health legislation.
- 62. We believe that the title of the AWI legislation should be changed to focus on support rather than incapacity e.g. Supported/Assisted Decision-Making (Capacity) Ac
- 63. It is of critical importance that the existing Acts are suitably aligned and coherent with planned future legislative developments and the potential for a new multi-institutional approach to accountability and justice.



Lorne Berkley Strategic Lead: Evidence and Rights Scottish Commission for People with Learning Disabilities <u>lorne.b@scld.co.uk</u>

Contact us

Website: www.scld.org.uk Twitter: @SCLDNews Facebook: @ScotCommission Instagram: @scldnews

To find out more about SCLD and the work we do, please visit: <u>www.scld.org.uk</u>

The Scottish Commission for Learning Disability Suite 5.2 Stock Exchange Court 77 Nelson Mandela Place Glasgow G2 1QY

