



Consultation Response

Scottish Mental Health Law Review – Stage 1

The Scottish Commission for
People with Learning
Disabilities (SCLD)

May 2020



Background

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* (2013)¹ and *The keys to life* Implementation Framework (2019-2021)². The implementation framework defines a learning disability as follows:

"A learning disability is significant and lifelong. It starts before adulthood and affects a person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate." (*The Keys to life*, 2019-2021, p.9)

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.

SCLD is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD is a knowledge hub - building an evidence base, sharing how policy is being implemented and developing a shared understanding of what really works.

Introduction

SCLD welcomes the opportunity to respond to Stage 1 of the Independent Review of Mental Health Law in Scotland (SMHLR). We support the main aim of the Review, as set out in the Terms of Reference: "to improve the rights and protections of persons who may be subject to the existing provisions of mental health, incapacity or adult support and protection legislation as a consequence of having a mental disorder, and remove barriers to those caring for their health and welfare."¹

The Independent Review of Learning Disability and Autism in the Mental Health Act (IRMHA) found that people with learning/intellectual disabilities experience indirect discrimination under Scotland's Mental Health Act. It also highlighted a number of human rights issues relating to Scotland's Mental Health Law which have a worse

¹ SMHLR Terms of Reference (2020)

impact on people with learning/intellectual disability than on other groups of people².

In our submission to IRMHA, 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 intellectual/learning disabilities and risks legitimatising the restriction of rights including detention and non-consensual treatment on the basis of learning disability.³ We strongly support the IRMHA recommendation that learning disability should not be defined as a form of 'mental disorder' in Mental Health Law. However, we recognise that this necessitates wider legislative reform to Mental Health and Capacity Law to ensure people with learning disabilities can attain the highest possible standard of mental and physical health while promoting and protecting their human rights, and avoiding practices which may be discriminatory.

The Covid-19 crisis has brought unprecedented challenges at a local, national and international level and the emergency response has shone a light on the need for laws and ways of working that safeguard health and well-being and are applied in a non-discriminatory manner. It has become increasingly clear that as Scotland begins its process of recovery from this crisis, things will not return to the way they were and that the challenge is to adapt to living alongside Covid-19 in 'a new normal'. This process of renewal will continue to necessitate changes to everyday life and require services, process and systems to adapt accordingly.

The psychological impacts of physical distancing and self-isolation and shielding, the wider trauma caused through living with the devastating effects of Covid-19, and the challenge of delivering health and social care services to vulnerable groups are all likely to significantly increase pressure on the delivery of mental health services. The impact of the continued need for physical and social distancing measures may provide fresh impetus for a further shift in the balance of care away from acute institutional settings to people increasingly receiving support, care and treatment, at home within their communities.

As the First Minister's Covid-19: A Framework for Decision Making states *"When things come apart, there is always the opportunity to put them back together differently. We can work together to design the Scotland we want to emerge from this crisis."*⁴ In our view, there is now a unique opportunity at to look at how

² Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

³ SCLD submission to IRMHA Stage 3 (2019)

⁴ Scottish Government (2020) Covid-19 Decision Making Framework

Scotland can do things radically different to achieve positive outcomes for people with learning/intellectual disabilities and others and carefully examine what this means for Mental Health legal structures, systems and process in the context of Covid-19. The need for transformational change has arguably become more urgent not less.

However, this process of transformation should not begin from a blank slate. SCLD believes that reform of Mental Health and Capacity Law in Scotland should be built in line with the UN Convention on the Rights of Person with Disabilities (CPRD) as recognised in Scotland's National Disability Strategy⁵, Scotland's Mental Health Strategy 2017 - 2027⁶, the Scottish Government's consultation on the reform of the Adult's With Incapacity (Scotland) Act (AWI) and the Independent Review of Learning Disability and Autism in the Mental Health Act⁷ (IRMHA).

The SMHLR provides the opportunity for a paradigm shift in Scotland's Mental Health and Capacity Law to promote the highest possible standard of mental and physical health; establish equality and non-discrimination in how people experience their rights; supported decision making structures which respect individuals rights, will and preferences, and proportionate decision making to ensure any limits to rights must be applied equally and do not discriminate against certain groups in any way. It is essential that people with learning/disabilities are fully involved and consulted in this on-going process.

The Mental health (Care and Treatment) (Scotland) Act 2003 came into force in 2005 - how well does it work at the moment?

Care, treatment and support

1. Risks to health, liberty, and a denial private and family life and independent living through delayed discharge and out-of-area placements

SCLD has concerns that when people with learning disabilities are admitted to Assessment and Treatment Units (ATUs) or other mental health wards, they often experience delayed discharge and remain in hospital when there is no clinical need for them to be there. This is often due to delays in setting up the package of care they need to live in the community.

⁵ Scottish Government (2016) A Fairer Scotland for Disabled People - Our Delivery Plan to 2021 for the UNCRPD

⁶ Scottish Government (2017) Mental health Strategy 2017-2027

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

The 2019 Mental Health and Learning Disability Inpatient Census⁸ showed that 229 (7%) of adult mental health, addiction or learning disabilities inpatients had a diagnosis of learning disability, 146 of these were in learning disability wards, and of these 85% were subject to compulsory measures. It found that 37% of these patients in learning disability wards were delayed discharges. The longest delays to discharge were for patients in learning disability units, both non-forensic (760 days) and forensic (786 days). For adults in learning disability wards the average (median) length of stay was 799 days compared with an average of 142 days for all patients in adult mental health, addition or learning disability wards. The Inpatient Census also showed that 40 patients with a diagnosis of learning disability or autism were in Out of Scotland NHS placements – this was 32% of all such placements.

Delayed discharge for people with learning/intellectual disabilities has been a persistent issue. The Coming Home Report in 2018 highlighted the issue of delayed discharge and out-of-area placements and found that of those classified as delayed discharge, 22% had been in hospital for more than 10 years and another 9% for five to ten years.⁹ A 2016 monitoring report of learning disability wards by the Mental Welfare Commission found that that 32% of people in learning disability wards were delayed discharge.¹⁰

SCLD is concerned that delayed discharge can breach the right to liberty and may exacerbate mental distress and ill health infringing on the right health and even the right to freedom from inhuman and degrading treatment. Delayed discharge also denies people with learning/intellectual disabilities their right to an independent life and entails a lack of access to support for daily living skills and their long-term removal from family and community. They may also lose the support they previously had in the community, their tenancy can be put at risk and benefit payments stopped¹¹.

The Coming Home report found that the main reasons given by HSCPs for delayed discharges were lack of service provision and lack of suitable accommodation, particularly self-contained accommodation for people with complex needs and lack

⁸ Mental Health & Learning Disability Inpatient Census and Out of Scotland NHS Placements Census (2019)

⁹ Coming Home (2018) A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs

¹⁰ Mental Welfare Commission for Scotland (2016) No through road: People with learning disabilities in hospital

¹¹ Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

of funding¹². Sections 26-27 in the Mental Health Act place duties on local authorities to provide services to support people to live in the community and promote well-being. However, the IRMHA found no evidence that these sections of the Mental Health Act are being enforced¹³. SCLD advocates increased availability and accessibility of learning disability nurses and greater emphasis on preventative services and crisis support. We believe there is a need for more joined up discharge planning and are working with a wide range of partners including the Scottish Government to promote this and encourage a shift in resources to towards wider provision of community-based health and social care services.

Recommendation: Implementation of the IRMHA recommendation that Scots' law should recognise the right to independent living, alongside strengthened duties on HSCPs to provide longer term community-based support and a requirement for this to be adequately resourced. SCLD believes the Law should also formally recognise the need for support for people with learning/intellectual disabilities to communicate their views, have meaningful choice over where they live and who they live with and be involved in planning and consulted about decisions.

2. Risks to health, to liberty, and to life, through inappropriate use of psychotropic medication

SCLD is concerned by evidence that, antipsychotic medications are being used to manage 'problem behaviours' with widespread use of 'off-label prescribing' of these medications for people with learning disabilities. Research by the SLDO found that adults with learning disabilities are prescribed antipsychotic drugs at much higher rates than reported rates of psychosis among people with learning disability¹⁴. These findings are supported by a population-based cohort study of 1023 adults with intellectual disabilities which showed that 49.5% were taking some form of psychotropic drug, with 23.5% taking an antipsychotic drug despite only 4.4% having a psychotic disorder. There was a similarly high rate of prescription of other drugs such as antidepressants, anxiolytics, and mood stabilisers.¹⁵ These psychotropic drugs are frequently prescribed to people with learning disabilities on a long-term basis despite significant side effects which pre-dispose to premature mortality,

¹² Coming Home A Report on Out-of Area Placements and Delayed Discharge for people with Learning Disabilities and Complex Needs, Scottish Government (2018)

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

¹⁴ SLDO (2017) 10 years of anti-psychotic prescribing in Scotland.

¹⁵ Public Health England (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England

including obesity, metabolic syndrome, and diabetes¹⁶ and with no reliable evidence of effectiveness beyond sedation.¹⁷

In our experience, behaviour perceived as challenging is very often a means of communication by people with profound and multiple needs and may be a response to inappropriate environments or support. The use of psychotropic medication to manage such behaviour as opposed to the purposes for which it was developed and approved raises a number of human rights concerns including absolute rights such as the right to life and rights to freedom from torture, inhuman and degrading treatment. We are also concerned that they are frequently administered on a compulsory basis often in the absence of appropriate structures for supported decision-making.

SCLD strongly supports the IRMHA recommendation for a clinical review of prescribing practice in psychotropic medication which considers and make recommendations on developing a national approach to the use of antipsychotic medication and other psychotropic medication for children and adults with learning/intellectual disabilities; stopping the use of antipsychotics to control behaviour and requirements for supporting withdrawal from antipsychotic medication¹⁸.

Recommendation: Mental Health and Capacity law, policy and practice requires reform to move away from inappropriate use of medication for people with complex needs towards increased focus on other forms of support such as Positive Behavioural Support; and individually tailored community based care which take a personal outcomes approach. All use of psychotropic medication should be accompanied by structured reviews which are accessible, incorporating best practice on shared decision making and supporting people with learning/intellectual disabilities to have an understanding of alternatives and side effects.

3. Restraint and seclusion

SCLD has concerns about the use of seclusion, physical restraint and chemical restraint (through medication), the implication this has for human rights and the lack of disaggregated data available to determine the extent of the problem in Scotland.

¹⁶ Tyrer, P & Cooper, S (2014) Drug treatments in people with intellectual disability and challenging behaviour (2014)

¹⁷ SLDO (2017) 10 years of anti-psychotic prescribing in Scotland.

¹⁸ Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

As part of IRMHA, a freedom of information request was submitted on how many prosecutions there have been under the 'duty to inquire' on local authorities (section 33). However, the Crown Office and Procurator Fiscal Service was unable to provide information on how often it had been used to protect people with learning/intellectual disabilities and autism who have experienced abuse or neglect under the Mental Health Act¹⁹.

SCLD believes the use of practices such as restriction of liberty, restraint and seclusion must be strictly limited and rigorously monitored. Furthermore, there must be consistency in their use across mental health, education, social care and criminal justice.

Recommendation: National human rights-based standards and monitoring of restrictive practices across all settings which is aligned with the on-going work to incorporate the UNCRC into Scots' law.

Are there groups of people whose particular needs are not well served by the current legislation? What would improve things?

The last monitoring report of learning disability wards by the Mental Welfare Commission found that 12 of the 18 units for people with learning disability in Scotland (excluding forensic units) in 2015 were thought to be inadequate. Reasons for this included the lack of availability of indoor or outdoor space, inadequate facilities to undertake assessment and treatment, and poor maintenance, decor or cleanliness. Many of these issues had also been identified in a previous report in 2011.²⁰

As discussed previously, the IRMHA also published evidence that people with learning/intellectual have their liberty restricted for longer periods of time than other groups under Scotland's mental health law. On average the length of detention for people with learning/intellectual disability and no other mental health diagnosis was almost double that for those people without learning disability. People with learning/intellectual disabilities who have other mental health conditions are also detained for longer than people without learning/intellectual disabilities. Furthermore, treatment is given without consent for much longer than

¹⁹ Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

²⁰ Mental Welfare Commission for Scotland (2016) No through road: People with learning disabilities in hospital

for other people with 'mental disorders' both in hospital and under compulsory treatment orders in the community²¹.

In evidence to IRMHA, people with learning/intellectual disabilities reported they can find it hard to challenge decisions made under the Act. A number of issues were raised including information about the Mental Health Act not being accessible, a lack of information about people's rights under the act, and Mental Health Tribunal papers being too difficult to understand preventing people understanding what was happening to them and knowing how to take part in decisions²².

Recommendation: In delivery of appropriate services to people with learning/intellectual disabilities a key test should be whether care, treatment and support is fully accessible, available, acceptable and of a good quality ('AAAQ'). Law and practice must also ensure that people with learning/intellectual disabilities can participate in decision-making processes and that duty bearers are accountable. It is critical that the views of people with learning/intellectual disabilities have the opportunity to inform and shape changes to the law and how these are implemented.

Protecting Human Rights and changes since the Act came into force in 2005

Since the Mental Health (Care and Treatment) (Scotland) Act 2003 came into force in 2005 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)²³ which the UK ratified in 2007. Although the CRPD is not incorporated in domestic law, it has become increasingly influential in judicial decisions and the European Court of Human Rights is required to take it into account, as a higher source of international law, when interpreting ECHR rights²⁴. This had led to increasing recognition that Scotland's system of Mental Health and Capacity law, which was widely regarded as world leading when introduced, is no longer fully compliant with international human rights standards.²⁵

The UNCRPD 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. This requires not only promotion of rights but also the active removal of

²¹Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

²²Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

²³Convention on the Rights of Persons with Disabilities (2006)

²⁴Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD

²⁵Mental Welfare Commission (2017) Scotland's Mental Health and Capacity Law: The Case for Reform.

barriers preventing the full and equal enjoyment of human rights by persons with disabilities.²⁶ In the UK's first CRPD review in 2017, the Committee on the Rights of Persons with Disabilities made a number of concluding observations including the need for the UK to abolish substitute decision-making practices, build supported decision-making in legislation, policy and practice, repeal legislation that authorizes non-consensual treatment and compulsory treatment on the basis of impairment.²⁷ The UN Special Rapporteur on the rights of persons with disabilities has made several recommendations on how reforming mental health laws and practice can better protect UNCRPD rights²⁸.

SCLD believes there is scope for human rights-based law and practice in Scotland to be strengthened by drawing on the advice and expertise from national and international experts in academia, the UN and WHO. It is also critical to build on the findings and recommendation of IRMHA , the second National Action Plan for Human Rights²⁹ and the work of the National Taskforce to incorporate international human rights law into Scots law.³⁰

Recommendation: The legislative framework of mental health and capacity law in Scotland must reflect international human rights standards by ensuring equality and non discrimination in how people experience their rights; enshrining supported decision making structures which respect individuals rights, will and preferences, and emphasising proportionate decision making to ensure any limits to rights are applied equally and do not discriminate against certain groups in any way. It is essential that people with learning/intellectual disabilities continue to be considered and fully involved and consulted throughout this process.

Maximising a person's ability to make their own decisions and give effect to them

At present, Mental Health and Capacity Law in Scotland allows decisions to be made for an individual by a substitute decision maker in their 'best interests' rather than in accordance with their expressed will and preference. Article 12 of the CRPD requires that people with disabilities have access to the support they require to

²⁶ Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD

²⁷ Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland (2017)

²⁸ Rights of persons with disabilities. Report of the Special Rapporteur on the rights of persons with disabilities (2019)

²⁹ SNAP 2: Proposal for Scotland's second National Action Plan for Human Rights (2019)

³⁰ National Taskforce for Human Rights Leadership (2019)

make decisions and exercise their legal capacity and that appropriate and effective safeguards are in place to prevent abuse in this regard³¹.

The UNCRPD Committee in General Comment No.1 (2014) describes legal capacity and mental capacity as distinct concepts:

- Legal capacity is the ability to hold rights and duties (legal standing) and to exercise those rights and duties (legal agency) which is key to accessing meaningful participation in society.
- Mental capacity refers to decision-making skills of a person, which vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors.³²

Therefore, for people with learning/intellectual disabilities to be able to exercise their legal agency they may require access to ‘supported decision-making’. This can take several forms including:

- By one or more trusted persons, peer support and advocacy (including self-advocacy)
- Assistance with communication, appropriate to the needs of the individual including those who use non-verbal forms of communication to express their will and preferences
- Advance Care planning including support to a person to complete an advance planning process
- Special support in legal and administrative proceedings including accessible information and accessible services³³

In line with IRMHA, SCLD believes Mental Health and Capacity Law in Scotland should reflect CRPD Article 12 rights more strongly. Consideration should be given to enhanced legal principles to reflect the need for individuals to have support for the exercise of legal capacity, including provision for the appointment of an ‘official supporter’, a statement of rights, will and preferences alongside human rights assessments and increased resources for the provision of independent advocacy and national standard for accessible communication. Such reforms may also require a review of safeguards to protect individuals from potential abuse and increased support and education for non-professionals to help them understand and comply with the principles of supported decision-making.

³¹ Convention on the Rights of Persons with Disabilities (2006)

³² CRPD Committee (2014) General Comment No.1

³³ CRPD Committee (2014) General Comment No.1

We also believe that Scotland requires a national framework for Supported Decision-Making. People First have produced a Framework for Supported Decision-Making³⁴ which sets out a template for understanding 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.

Recommendation: Mental Health and Capacity Law in Scotland should reflect Article 12 rights together with a national supported decision-making framework recognised in law to support people with learning/intellectual disabilities and others to make decisions, exercise their legal capacity and have their rights, will and preferences respected on the same basis as others.

The Act has a set of legal tests to justify making someone subject to compulsion. Would you suggest any changes to these?

At present, compulsion under Scotland's mental health law applies a diagnostic threshold based largely on the concept of 'mental disorder' and capacity assessments³⁵. If a medical professional assesses that a person has a learning/intellectual disability (currently defined in law as a mental disorder) and 'significantly impaired decision-making ability' (SIDMA) they can be subject to interventions such as detention and medical treatment regardless of their expressed will or preference. The consequences of this denial of individual autonomy, based even in part on a diagnosis such as learning disability, is potentially discriminatory. It is particularly concerning in light of a lack of available and robust mechanisms to support the exercise of legal capacity in decision making.

As already stated, SCLD supports the removal of learning disability from the definition of 'mental disorder' accompanied by wider legislative change which puts duties and structures in place to support people with learning disabilities to make decisions and have their rights, will and preferences respected. We recognise, however, that equal enjoyment of human rights without discrimination does not mean that rights can never be denied or limited³⁶.

Where people with learning/intellectual disabilities also have a mental health condition and/or pose a risk to themselves, there may be circumstances in which individuals require care and treatment for a limited period to protect their right to

³⁴ People First (2017) Framework for Supported Decision Making

³⁵ Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health and Capacity Law: the Case for Reform (2017)

³⁶ Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD

life and to enjoy of the *highest attainable standard* of physical and mental *health*. However, there are widespread concerns about how ‘capacity’ and ‘significantly impaired decision-making ability’ (SIDMA) are assessed by clinicians and practitioners and at the lack of clear guidance for practitioners on how to assess SIDMA.

The current criteria of SIDMA are not defined in law and the Code of Practice explains that whilst the concept is considered to be separate to that of "incapacity", in practice similar factors will be considered as when assessing incapacity under the AWI³⁷. People First, in their response to Sandra McDonald’s Capacity Assessing Survey for SMHLR, have stated that “there is no agreed, reliable and accepted method of assessing capacity in Scotland and, while conducted mostly by highly educated and trained professionals, it remains as an entirely subjective and unscientific process based mainly on prejudicial assumptions about intellectual impairment”³⁸.

Furthermore, a report published by the Mental Welfare Commission 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’. Capacity assessments can often be made by professionals on the basis of how the individual presents on a given day and with little or no knowledge or involvement of the individual and their background or their carers, family, partners, friends and professionals.

SCLD believes there is an argument for revisiting eligibility criteria for compulsion under mental health and capacity law in Scotland so that the circumstances under which it is permissible are “de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis”³⁹. We recognise, however, there is a significant challenge in establishing a new non-discriminatory threshold for involuntary interventions.

SCLD believes reform should be considered which introduces a rebuttable presumption of capacity and makes the individual’s will and preferences paramount. This provision of appropriate support would need to be demonstrated before statutory interventions were considered. We believe that there is also merit in the wider application of ‘human rights assessments’ as outlined by IRMHA. These would be required before any intervention that override the will and preference of any

³⁷ Mental Welfare Commission & Centre for Mental Health and Capacity Law, ‘Scotland’s Mental Health and Capacity Law: the Case for Reform (2017)

³⁸ People First (2020) Response to SMHLR Capacity Assessing Survey

³⁹ Gurbai, Sandor and Martin, Wayne (2018) Is Involuntary Placement and Non-Consensual treatment Ever Compliant with UN Human Rights Standards?

individual was permissible. Any such intervention would need to be justified on the basis of an assessment of an individual's competing rights and their expressed will and preference.

Recommendation: Explicit recognition in law of a rebuttable presumption of capacity which gives primacy to the individual's will and preference, alongside 'human rights assessments' where interventions may contravene this.

The Act requires a local authority to provide services for people with a mental disorder who are not in hospital, which should be designed to minimise the effect of mental disorder on people and enable them to live as full a life as possible (sections 25 and 26 of the Act). Do you think this requirement is currently met? Does more need to be done to help people recover from mental disorder?

Learning/intellectual disability is a lifelong disability yet defined as a 'mental disorder' it has been predominantly understood as a medical condition in Scotland and the UK. People with learning disabilities have told us that they consider the term 'disorder' to have negative connotations which they find stigmatizing. Historically, people with learning disabilities have been denied key civil, political and social rights. The policy of 'institutionalisation' resulted in a lifetime of segregation for people with learning disabilities in which they experienced societal '*othering*⁴⁰ and were denied full rights as citizens. SCLD believes that defining learning disability as a 'mental disorder' has served to perpetuate this marginalisation and discrimination.

The Mental Health Act requires Local Authorities to provide care and support services for people with learning/intellectual disabilities. Sections 25-26 place duties on local authorities to provide care and support services to support independent living and promote wellbeing and social development including social, cultural and recreational activities and training and employment assistance for people over school age. Section 27 also places a duty on local authorities to provide assistance with travel.

SCLD shares the Health and Social Care Alliances' concerns at the general lack of awareness of these rights as well as an apparent lack of monitoring or oversight⁴¹. Additionally, whilst the duties set out in sections 25-27 engage a wide range of human rights within the UNCRPD there is significant evidence that people with learning/intellectual disabilities do not fully enjoy these rights. Rather, people with

⁴⁰ Parr & Butler (1999) Geographies of Illness, Impairment and Disability

⁴¹ Alliance (2020) Response to SMHLR Stage 1

learning disabilities continue to face barriers to active citizenship, full engagement in civil and public life and a lack of access to education⁴², employment⁴³, relationships⁴⁴, and family lives⁴⁵.

Recommendation: Mental Health and Capacity law should have more of a focus on promoting people's social, economic and cultural rights, including rights relating to housing, education, work and standards of living and health. There should be more emphasis on raising awareness of these rights alongside greater scrutiny and oversight of these duties and increased transparency about measures being taken to implement them.

Do you think the law could do more to raise awareness of and encourage respect for the rights and dignity of people with mental health needs?

People with learning disabilities continue to experience significant discrimination and difficulties in overcoming environmental, organisational and attitudinal barriers which mean they are often excluded both as active citizens and rights holders.

SCLD agrees with the Health and Social Care Alliance that mental health and capacity law could include provisions specifically aimed at increasing awareness of rights and ensuring they are respected, protected and fulfilled⁴⁶. Article 8 of the UNCRPD places a duty on the state to:

- Raise awareness and foster respect for the rights and dignity of disabled people.
- Combat stereotypes, prejudices and harmful practices relating to disabled people.
- Promote awareness of the capabilities and contributions of disabled people.

It is critical that professionals take the time to listen to and understand people with learning/intellectual disabilities, and respond in a person centred way. We believe legislative reform in Scotland requires a cultural shift towards the social and human rights model of disability. This will require training and support for those working at various levels of mental health and capacity law including lawyers, social workers,

⁴² ENABLE (2016) #Included in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability

⁴³ McTeir et al (2016) Mapping the Employability Landscape for People with Learning Disabilities in Scotland

⁴⁴ SCLD (2018) Safe and Healthy Relationships: Empowering & Supporting People with Learning Disabilities

⁴⁵ SCLD (2018) Children's Rights: Consultation on incorporating the UNCRC into our domestic law in Scotland

⁴⁶ Alliance (2020) Response to SMHLR Stage 1

the Mental Health Tribunal, independent advocates, police, as well as mental health professionals.

Recommendation: Mental health and Capacity law should incorporate Article 8 rights as set out in the UNCRPD to increase awareness of rights and ensure they are respected, protected alongside training and support to engender a cultural shift towards the social and human rights model of disability.

Based on your experience, are there any difficulties with the way the 3 pieces of legislation work separately or the way they work together? What improvements might be made to overcome those difficulties?

The Adults with Incapacity (AWI) Act also uses the concept of 'mental disorder' and people with a learning/intellectual disability represent 45% of all welfare guardian orders⁴⁷ under the Act. In recent years there has been a steady increase in the number of guardianship order being granted and there has been a particularly sharp rise among young people aged 16-24.⁴⁸ Concern have been raised at the lack of automatic, periodic judicial scrutiny of guardianship orders under the AWI. This is particularly worrying with respect to indefinite orders which apply to 5% of people with learning/intellectual disabilities⁴⁹. Where indefinite guardianship is used to authorise deprivation of liberty, this may breach Article 5 of the European Convention as case law makes clear the need for regular review.

While the AWI Act is underpinned by a number of important principles which reflect human rights values, guardianship orders necessarily entail a serious restriction of choice, autonomy and privacy, and there a number of concerns about current practice. These include the legal principles not being well understood by legal, health and social care practitioners. People with learning/intellectual disabilities can also be denied due process rights in guardianship proceedings such as attendance at the hearing and sufficient access to independent advocacy. There are also concerns about the reliability of capacity assessments and poor practice which may undermine the actual or potential capacity of individuals and their right to be involved in decisions about their own support, care and treatment.⁵⁰

⁴⁷ Mental Welfare Commission Scotland (2018) Adult with Incapacity Act Statistical Monitoring 2017/18

⁴⁸ Mental Welfare Commission Scotland (2018) Adult with Incapacity Act Statistical Monitoring 2017/18

⁴⁹ Mental Welfare Commission Scotland (2018) Adult with Incapacity Act Statistical Monitoring 2017/18

⁵⁰ Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health and Capacity Law: the Case for Reform (2017)

The AWI Act and guidance state clearly that capacity is not an all or nothing concept and that assessment should refer specifically to a single decision or type of decision. However, People First point out that *'While it is true that Guardianship orders are required to specify the Guardianship and substitute decision-making powers granted by the courts, it is all too common that long lists of powers are included in the applications and the orders, often based on legal advice that more is better.'*⁵¹

Additionally they argue that, *'the day to day practice of psychiatry, of the courts, of the law, is to apply the label "incapable adult" as if it were a global concept'*. The effect of declaring someone an "incapable adult" as a result of a capacity assessment removes their legal capacity on the grounds of their intellectual impairment.⁵²

In its present form, the AWI Act raises a number of human rights concerns including Equal Recognition Before the Law (Article 12, CRPD) and Deprivation of Liberty (Article 5, EHRC; Article 14, CRPD). In 2018 the Scottish Government Proposals for Reform to Adults with Incapacity (Scotland) Act 2000 recognised the need for reform in *"seeking to achieve is an over-arching support mechanism which will maximize the autonomy and exercise of legal capacity for persons with impaired capacity so that genuine non-discriminatory respect is afforded for individuals with rights and preferences"*.

SCLD believes, the IRMHA recommendation to remove learning disability from the term 'mental disorder' necessitates transformative change to the legislative framework for both mental health and capacity law in Scotland. This must seek to promote and safeguard health and well-being, ensure a non-discriminatory approach to compulsory interventions and protect existing rights in law for people with learning/intellectual disabilities.

The Mental Welfare Commission for Scotland 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.'*⁵³ In our view, it is this challenge that the SMHLR must embrace moving forward.

Recommendation: The whole legislative framework that impacts the lives of people with learning disabilities requires reform and re-alignment to ensure a coherent and

⁵¹ People First (2020) Response to SMHLR Capacity Assessing Survey

⁵² People First (2020) Response to SMHLR Capacity Assessing Survey

⁵³ Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health and Capacity Law: the Case for Reform (2017)

non-discriminatory approach to care, support and treatment which reflects UNCRPD and ECHR requirements.

SCLD thanks the Scottish Mental Health Law Review team for the opportunity to submit to Stage 1 of the Review.

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