



Consultation Response

The Independent Review of Learning Disability and Autism in the Mental Health Act – Stage 3

The Scottish Commission for
Learning Disability
November 2019

The Scottish Commission for Learning Disability (SCLD) welcomes the opportunity to respond to Stage 3 of The independent review of Learning Disability and Autism in the Mental Health Act. SCLD is an independent charitable organisation and strategic 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)

SCLD is committed to creating an environment in which systems and culture are changed and in which people with learning disabilities have opportunities and are empowered to improve their own lives. SCLD is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

We welcome the opportunity to comment on the findings of the Review and to consider how the legislative framework in Scotland can best promote and protect the rights of people with learning disabilities to empower them to live their best lives.

¹ *The Keys to life* (2013)

² Scottish Government (2019) *The Keys to life* Unlocking Futures for People with Learning Disabilities Implementation framework and priorities 2019-2021

Below are a list of key points SCLD believes should be considered as we move forward.

1. Legislative change and compliance with EHCR and UNCRPD

- Move towards human rights respecting culture for people with learning disabilities in Scotland which builds on the EHCR and the UNCRPD

2. Learning disability understood as disability

- Develop a clearer understanding of learning disability which takes a truly social model approach
- Ensure the right of people with learning disabilities to exercise their legal capacity

3. Support for decision making

- Develop a framework for supported decision making in line with wider changes in the Adults with Incapacity Review
- Ensure funding for independent advocacy supported by accredited high quality training on a range of communication styles
- Develop accessible communication standards with people with learning disabilities

4. Psychological interventions and prescribing psychotropic medication

- Commission a large scale review to determine the extent overprescribing of psychotropic medication is a public health problem for people with learning disabilities in Scotland

5. Rights to support care and treatment

- Hold national-level conversations about the potential for wider legislative change based on international treaties which is cognisant of developments surrounding the UNCRC in Scotland
- Ensure the right to independent living is well resourced

6. Specialist health and social care environments

- Improve access to appropriately tailored support, care and treatment for people with learning disabilities in mainstream mental health services
- Improve community-based preventative mental health services

7. Professional Decision Making

- Ensure professional decision making is proportionate and protects an individuals over all rights
- Ensure that detention and compulsory treatment is not based on learning disability

8. Monitoring of decision making

- Support people with learning disabilities to become aware of their human rights and to be able to realise them; accompanied by opportunities for redress

9. Support care and treatment for offenders

- Ensure funding for intermediaries to support people with learning disabilities who come into the criminal justice system
- Support rehabilitation of offenders through community based sentences where appropriate

10. Legal implications

- Create transformational change for people with learning disabilities by ensuring their strengths and needs are reflected across all relevant legislation and consider the role the UNCRPD in supporting this.

What Scotland needs to do

We think that Scotland’s mental health law needs to change for autistic people and people with learning disability.

We think that the law needs to change to comply with the United Nations Convention on the Rights of Persons with Disabilities.

We also think that it needs to change to comply with the European Convention on Human Rights in full.

1. Legislative change and compliance with EHCR and UNCRPD

SCLD agrees with the Review’s proposal that Scotland’s mental health law needs to change for autistic people and people with learning disability. We believe that, at present, the Mental Health (Care and Treatment) (Scotland) Act 2003 (Mental Health Act) fails to adequately promote and protect the human rights of people with learning disabilities, and leads to practices which are inherently discriminatory towards them.

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’*³ and were denied full rights as citizens. The stigma and multi-layered exclusion which stemmed from this persists today and people with learning disabilities continue to face barriers to active citizenship and a lack of access to education, employment,

³ Parr & Butler (1999) *Geographies of Illness, Impairment and Disability*

relationships, and family lives⁴. SCLD believes that the inclusion of learning disability as a 'mental disorder' has served to perpetuate this marginalisation and has legitimatised the restriction of rights including detention and non-consensual treatment on the basis of learning disability.

When the Mental Health Act was enacted in 2003, it was regarded by many as a world-leading piece of legislation in terms of its underlying principles and rights-based approach.⁵ However, since then there have been significant developments in human rights law and practices, not least the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁶. The UNCRPD, which was ratified by the UK in 2007, 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 barriers preventing the full and equal enjoyment of human rights by persons with disabilities.

All legislation in Scotland must also be compatible with the European Convention of Human Rights (EHRC) as set out in the Human rights Act 1998.⁷ Furthermore, under the Scotland Act 1998 Scottish Ministers must observe and implement the UK's international obligations and human rights treaties.⁸ In the UK's first UNCRPD 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,

⁴ SCLD (2018) *Children's Rights: Consultation on incorporating the United Nations Convention on the Rights of the Child into our domestic law in Scotland*

⁵ Mental Welfare Commission (2017) *Scotland's Mental Health and Capacity Law: The Case for Reform*.

⁶ *Convention on the Rights of Persons with Disabilities (2006)*

⁷ *Scotland Act 1988 and Human Rights Act 1998*.

⁸ *Scotland Act 1998*.

repeal legislation that authorizes non-consensual treatment and compulsory treatment on the basis of impairment.⁹

We acknowledge the challenge of legislative change that ensures mental health law in Scotland for people with learning disabilities complies with both the EHRC and the UNCRPD. However, we agree with the Review that compliance with UNCRPD necessitates:

- 1.** Change led by people with learning disabilities: Scotland has to fully involve people with learning disability in developing, implementing and monitoring the laws and policies that support Scotland's commitment to the UNCRPD and other human rights standards.
- 2.** A 'paradigm shift': People with learning disabilities must be equal citizens who hold rights and have equal standing before the law, and support to make full use of their legal capacity.
- 3.** Equality and non-discrimination in how people experience their rights: A characteristic such as disability can never be used to justify a limit on human rights.
- 4.** 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.
- 5.** 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.

⁹ Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland (2017)

We recognise that this 'paradigm shift' presents numerous challenges from both a legislative and political perspective. To achieve it will require a significant shift in both culture and practice as well as a significant of additional resources.

How we understand autism, learning disability and mental health

We suggest that Scotland needs to move to understanding autism and learning disability as disabilities, not as mental disorders.

We think that Scotland's mental health services for autistic people and people with learning disability need to move to a human rights culture.

In Scots law, everyone is presumed to have legal capacity. We suggest that it should not be possible to challenge the legal capacity of autistic people or people with learning disability.

2. Learning disability understood as a disability

SCLD strongly welcomes the Review's proposals that autism and learning disability should be defined as disabilities, not as 'mental disorders'.

Defined as a 'mental disorder', a learning disability has been understood as a medical condition, diagnosable by psychiatrists or clinical psychologists, and subject to medical care and treatment.

People with learning disabilities have told us that they consider the term 'disorder' to have negative connotations which they find stigmatizing. At our engagement event for this consultation, individuals with learning disabilities were clear that learning disability should not be defined under a mental health banner. They felt their learning disability to be an integral part of their experience, for which there is no medical

'cure' or treatment. However, people with learning disabilities were clear they did not want disability to define them and instead wanted to be treated as individuals who may require additional support.¹⁰

Chappell (2001) explains that, historically, medical professionals created systems of knowledge which defined disability as an 'individual pathology.' This led to an understanding of disability as located within the individual, and any difficulties they face as the direct and inevitable consequence of impairment. There has been a particular tendency to apply this medical model of disability to people with learning disabilities.¹¹

In our view, understanding learning disability as a 'medical disorder' adopts this 'individualised approach' which emphasises the challenges people with learning disabilities face as inherent to their impairments. In doing so, it ignores societal structures and practices that deny people with learning disabilities access to active participation in society and the full enjoyment of their rights.

We welcome the proposal by the Review for Scotland to adopt the UNCRPD definition which recognises that: *'Disability results from the interactions between persons with impairments, and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others¹².'*

We agree with People First that: *"To follow the social model of disability, any number of barriers to inclusion and citizenship creates the disability but it is the responsibility of society or community to deal with the barriers, rather than treating the disabled person for their reactions to the barriers¹³."*

¹⁰ SCLD (2019) Focus Group Feedback Report

¹¹ (2001) Chappell, A British Journal of Learning Disabilities. Making connections: the relevance of the social model of disability for people with learning difficulties

¹² Convention on the Rights of Persons with Disabilities (2006)

¹³ People First (2019) Response to the Independent review of Learning Disability and Autism Stage 3

In common with People First, we do not recognise what the Review refers to as the 'disability model'. As People First point out:

"Both the Social Model and the Medical model are models of Disability - they tell us the different ways of seeing disability and thinking about it. Something called a "Disability model" doesn't make sense - what is it a model of? If it's a Disability model of Disability, it tells us nothing."¹⁴

The review explains that using the 'disability model' a person with learning disabilities could be considered to have 'intellectual impairment' at all times and to have 'intellectual disability' when they experience stress, distress or serious limitation. We do not think this definition adequately captures the social, economic and cultural barriers that prevent people with learning disabilities enjoying full and effective participation in society. In our view, this definition risks narrowing our understanding of learning disability.

We also have serious reservations about how the new definition would be used in practice. The Review proposes that psychiatrists would both diagnose an 'intellectual impairment' and also diagnose that social and environmental barriers have caused a 'temporary disability'. In our view, this retains a focus on learning disability as a medical issue which requires treatment and will lead to the continued denial of rights for people with a learning disability on the basis of disability.

SCLD agrees with the Review that people with learning disabilities must be equal citizens who have equal standing before the law with access to support to make full use of their legal capacity.

Legal capacity is indispensable for the exercise of civil, political, social and economic and cultural rights. The denial of legal capacity for people with disabilities has led to their being deprived of fundamental rights including the right to start a family,

¹⁴ People First (2019) Response to the Independent review of Learning Disability and Autism Stage 3

reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty.¹⁵

The UNCPRD Committee views 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.¹⁶

At present under Scotland's Mental Health Law, a person's legal capacity can be denied if a medical professional assesses that a person's mental capacity is limited. If a psychiatrist determines that someone has a learning disability and 'significantly impaired decision-making ability' they can be subject to interventions such as detention and non-consensual treatment.

We think these criteria should change. As the UNCPRD Committee recognises, the inability to exercise legal capacity is an impediment to the equal enjoyment of all human rights. Furthermore, in the mental health context, the ability to exercise legal capacity can be denied by involuntary interventions.¹⁷ Any denial of legal capacity or authorization for non-consensual interventions on the basis of a diagnosis such as a learning disability is discriminatory.

¹⁵ CRPD Committee (2014) General Comment No.1

¹⁶ CRPD Committee (2014) General Comment No.1

¹⁷ Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD in Scotland

Support for decision making

We suggest that Scotland should make change to comply in full with a key right in the Convention on the Rights of Persons with Disabilities, the right to equal recognition before the law.

To make it possible for autistic people and people with learning disability to have and use their legal capacity, Scotland would have to give strong support for decision making. We make a range of suggestions on how this support should be set up.

We also discuss how we think decisions should be made on psychological interventions, psychotropic medication, and at times of crisis.

3. Support for decision making

SCLD agrees strongly with the Review that Scotland needs to recognise all people as citizens who have equal standing before the law and support all people to exercise their legal capacity. We agree that changes in law with regard to legal capacity needs to be accompanied by strong rights to support for decision making, together with appropriate safeguards to ensure that the rights, will and preferences of learning disabilities are respected.

This aligns closely with Article 12 of the UNCRPD which 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*.¹⁸ It

¹⁸ Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD in Scotland

also requires States parties to create appropriate and effective safeguards for the exercise of legal capacity and these must include protection against undue influence.¹⁹

While Article 12 does not define 'support', the UNCRPD Committee interprets it as a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. This may involve someone choosing one or more trusted support persons to assist them in exercising their legal capacity for certain types of decision or calling on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. It also requires the provision of accessible information and communication and accessible services to remove barriers to the realisation of legal capacity. This includes the development and recognition of augmentative methods of communication, especially for those who use non-verbal forms of communication.²⁰

SCLD believes that supported decision making should be a flexible process that can be facilitated by different people at different times. However, we recognise that giving full effect to this in practice presents significant challenges. We are also cognisant that the feasibility of implementing the Review's proposals in a mental health context may be contingent on wider changes to other areas of legislation that impact on people with learning disabilities such as the Adults with Incapacity Act. In our view, a more fully developed and robust framework to enable supported decision making in practice than has been proposed is required for people with learning disabilities to exercise their legal capacity effectively.

We believe there needs to be a cultural shift in Scotland that recognises the importance of supported decision making. We agree with the Review that independent advocacy, 'decision supporters', unpaid carers, information from

¹⁹ Convention on the Rights of Persons with Disabilities (2006)

²⁰ CRPD Committee (2014) General Comment No.1

professionals and advance directives in the form of a 'statement of rights will and preferences' should all have a role to support people to make their own decisions in a mental health context.

We believe that independent advocacy has a central role to play in supported decision making for people with learning disabilities. Independent advocacy can empower people with learning disabilities through helping them to express their views and wishes, access information, make informed choices and address power imbalances.²¹ We believe it is important each person has an advocate consistently for each decision making process for which they require support.

However, independent advocacy is hugely underfunded in Scotland at present, despite of statutory requirements.²² Therefore, making support for decision-making a key responsibility of independent advocacy will require a significant commitment to additional and sustained funding. We agree with the Review that the law should place duties on Scottish Government and public authorities to ensure funding for everyone who needs an independent advocate. To support this, we believe there needs to be accredited, high quality training on a range of communication skills for independent advocates.

The review also identifies the role of 'decision supporter' as someone a person with learning disability chooses to help them to form their own decisions and to put these decisions into effect. This would be someone with personal relationships with the person, not a professional. The review does not make specific recommendations on decision supporters, as it expects the other independent review to do so. However,

²¹ SCLD (2018) A Stronger Voice? A scoping study of independent advocacy for people with learning disabilities

²² SCLD (2018) A Stronger Voice? A scoping study of independent advocacy for people with learning disabilities

it does say that that *“many unpaid carers could be decision supporters”*²³ and that carers could have an important role in working with non-instructed advocates. In these situations, there is obvious potential for conflicts of interest to arise at times. We believe, there is scope for a lack of clarity as to how these different roles and elements of support for decision making operate in practice. For example, there are potential conflicts between the current codes of practice for Independent Advocacy which state that *‘Advocates provide support on specific issues and provide information, but not advice’*²⁴ and what might be reasonably expected from someone offering support for decision-making.²⁵

We believe it is critical that appropriate safeguards are developed to ensure people with learning disabilities are genuinely supported to make decisions without undue influence. Furthermore, we think there must be safeguards to prevent people with learning disabilities effectively having decisions made for them by professionals on the basis of an assessment of their carer or family’s human rights.

At our consultation events, individuals with learning disabilities provided examples of where they had experienced disputes with their family regarding decision making. It was felt families could be overprotective at times. There were also examples of different family members disagreeing with each other over the person’s expressed decision. In one case, this had become a legal dispute. Some individuals also felt that professionals were more likely to listen to their families than to them.²⁶

To be able to make informed decisions, it is paramount that people with learning disabilities have access to accessible information about support, care and treatment.

²³ The independent review of Learning Disability and Autism, Stage 3 of the review (2019)

²⁴ SIAA (2019) Independent advocacy – Principles, Standards and Code of Best Practice (2019)

²⁵ People First (2017) Framework for Supported Decision Making

²⁶ SCLD (2019) Focus Group Feedback Report

We agree with the need to set standards for accessible communication and that people with learning disabilities should be central to developing these.

We believe there will need to be high quality training for all independent advocates on non-instructed advocacy to ensure consistency. There also needs to be training to raise awareness about non instructed advocacy amongst professionals, families and unpaid carers. We see a strong role for non-instructed advocacy in situations where, despite significant efforts having been made, it has not been possible to determine the will and preferences of an individual.

We agree with the Review that in such situations a “best interpretation of will and preferences” must replace the “best interests” determinations. However, it is paramount that people with profound and multiple learning disabilities are given every assistance to make decisions. There may be significant barriers faced by people with learning disabilities who have nonverbal communication. Therefore, support for decision making must encompass a range of communication tools including, but not limited to, Easy Ready Documents, Talking Mats and augmentative communication tools including Eye Gaze.

We see merit in the Review’s proposal for a statement of rights, will and preferences to replace advance statements. The review says there should be special regard for the rights, will and preferences of people with disability when decisions are being made, including decisions that could limit a person’s rights in any way. We agree that a key difference from advance statements is that the validity of any statement would not depend on whether a professional determined that some with a learning disability had enough mental capacity to make a statement. Rather, the statement would be directly and wholly addressed in any professional decision making that might limit the person’s human rights. Any such decision would, therefore, 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 protected the person's human rights overall.

4. Psychological interventions and prescribing psychotropic medication

The Review proposes that a person should only be given a psychological intervention *where 'there was no other possible way for the person to receive this benefit'*. We agree with the Review that there must be a move away from psychological interventions without consent. However, the Review highlights a growing evidence base for the effectiveness of psychological therapies for people with learning disabilities where these are tailored appropriately to someone's needs, and where professionals have the necessary skills and training. In light of this, we do not believe that psychological interventions should be considered an option of last resort.

We agree with the Review that to meet its human right duties Scotland has to move away from compulsory use of psychotropic medication for people with a learning disability. When people are prescribed psychotropic drugs we support the right to regular reviews of health and to a plan to come off these. However, it is essential that accessible information is available so that people are aware of these rights and that have access to any support they require to make such requests.

The Review says that: *"there is almost no evidence that psychotropic medication is helpful in supporting people with learning disability with their behaviour, and that psychotropic medications can cause life-limiting physical problems."*²⁷

We find this particularly worrying in light of evidence which suggests widespread 'off-label prescribing' of antipsychotic medications for people with learning disabilities'. Research by the Scottish Learning Disability Observatory (SLDO) found

²⁷ The independent review of Learning Disability and Autism, Stage 3 of the review (2019)

that adults with learning disabilities are prescribed antipsychotic drugs at much higher rates than reported rates of psychosis among people with learning disability²⁸.

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.²⁹ Furthermore, psychotropic drugs are frequently prescribed to people with learning disabilities on a long-term basis. This is despite significant side effects which pre-dispose to premature mortality, including obesity, metabolic syndrome, and diabetes³⁰ and with no reliable evidence of effectiveness beyond sedation.³¹

The review proposes that: *“Scottish Government should commission work that effectively promotes the appropriate prescribing and use of psychotropic medications by doctors, nurses and other professionals, for autistic people and people with a learning disability in Scotland... [and] should commission research to understand the health effects of current prescribing practice for autistic people and people with learning disability.”³²*

In our view, these proposals are not sufficiently robust and we are concerned that they may not lead to a significant change in prescribing practices by professionals. To seriously address this issue we think the Review’s proposals need to go much further. As part of the response to Winterbourne, Public Health England undertook a review

²⁸ SLDO (2017) 10 years of anti-psychotic prescribing in Scotland.

²⁹ Public Health England (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England

³⁰ Tyrer, P & Cooper, S (2014) Drug treatments in people with intellectual disability and challenging behaviour (2014)

³¹ SLDO (2017) 10 years of anti-psychotic prescribing in Scotland.

³² The independent review of Learning Disability and Autism, Stage 3 of the review (2019)

of prescribing of psychotropic drugs which estimated that up to 35,000 adults with learning disabilities were being prescribed an antipsychotic, an antidepressant or both without appropriate clinical justification.³³ We believe a similar large scale review may be required in Scotland to determine the extent of the public health issue for people with learning disabilities in Scotland.

Support, care and treatment

We suggest that autistic people and people with learning disability should be given rights in law to have access to the support, care and treatment that they need.

We also makes suggestions on how support, care and treatment could be provided for women, children and offenders, in ways that respect human rights.

We discuss some duties that would need to be placed on public authorities to make these rights real.

5. Rights to support, care and treatment

SCLD agrees with the review that Scotland needs to provide people with learning disability with rights to access the support, care and treatment that they need and choose.

We welcome the Review's recognition of Article 25 of the UNCRPD³⁴ on the right to health. We agree with the review that health care for people with learning disabilities must be available, accessible, acceptable and of good quality. We also agree with rights to health checks; rights to access to screening; assessment and diagnosis; and standards for accessibility. However, it should be noted that at the consultation event

³³ Public Health England (2015) Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England

³⁴ Convention on the Rights of Persons with Disabilities (2006)

with people with learning disabilities, the idea of health checks was met with suspicion. People were freighted that health checks would be compulsory and would lead to compulsory treatment. People were supportive of this idea if it did not lead to compulsory measures.

While we strongly support people with learning disabilities right to access support, care and treatment, we are not convinced that this necessitates separate learning disability legislation. SCLD however believes there could be a role for wider legislative change, based on international treaties, to ensure all people with disabilities have access to the support they need. SCLD would therefore welcome national level discussion on the potential of this as we move forward. Further, any discussions regarding new legislation or adopting international treaties must be cognisant of the ongoing work to incorporate the UNCRC into Scots law and any particular interplay or tensions. For example, Article 12 of the UNCRC (respect for the views of the child) and Article 25 of the UNCRPD (review of treatment in care). Therefore, any legislative change which stems from the review will need to be closely aligned with the on-going work to incorporate the UNCRC into Scots law.

Critically SCLD are concerned about unintended consequences from duties on local partnerships to provide specialist health and social care services and environments. In our view, these proposals will essentially create a separate mental health system for people with learning disabilities. In Scotland, we have had two decades of learning disability policy in which the strategic direction has been away from segregated services and institutions. Indeed, the implementation framework for Scotland learning disability strategy, *The Keys to life* is focussed on a whole system, whole population approach to achieving better outcomes for people with learning disabilities³⁵. This approach recognises that people with learning disabilities are not a homogenous

³⁵ Scottish Government (2019) *The Keys to life* Unlocking Futures for People with Learning Disabilities Implementation framework and priorities 2019-2021

group with identical needs. Rather, they are a diverse population of individuals who face a wide range of challenges and barriers.

People with learning disabilities frequently tell us that they want to be able to access the same services as everyone else and that people working in these services should have the skills and training to provide the support, care and treatment they require. At our consultation event, there was a strong message that people want to be treated as individuals rather than being identified by their disability or diagnosis. This was felt to be important in receiving support and healthcare that is appropriately tailored to them.³⁶

SCLD thinks there is a danger that health and social care services designed on the basis of an overarching diagnosis will not deliver individualised and personalised care. It may also mean that people with learning disabilities are increasingly denied access to wider services. Moreover, Winterbourne³⁷ and Whorlton Hall provide a clear warning that placing people with learning disabilities in segregated settings risks making them invisible and vulnerable to mistreatment and abuse.

Therefore, SCLD believes that people with learning disabilities will be safer and have their rights better protected when they live and use support and services alongside other citizens on an equal basis. We welcome the suggestion for a right to independent living in line with Article 19 of the UNCRPD together with duties on Scottish Government and local authorities to ensure enough resources to support this.

We have concerns that no groups of women with learning disabilities appear to have been met with as part of the review's engagement. As a result, in our opinion, the intersectionality between learning disability and gender has not been adequately

³⁶ SCLD Focus Group Feedback Report (2019)

³⁷ Department of Health (2012) Transforming care: A National response to Winterbourne View Hospital

considered by the review. Specifically, the particular disempowerment that women with learning disabilities experience when interacting with professional hierarchies. In particular, restrictions on reproductive rights and harmful forced practices that are experienced by women with learning disabilities have not been addressed by the review. Further, we would like to see more detail on the proposal to extend the corporate parenting duty to include any new service that is developed for people with learning disabilities.

Where support, care and treatment happens

We suggest that there should be a shift towards voluntary support and care that emphasises social support and care. We suggest a shift away from compulsory treatment in hospitals that emphasise medical treatment.

We suggest places where support, care and treatment should happen. This includes a new type of service which we call secure support centres.

6. Specialist health and social care environments

SCLD agrees with the review that there should be a shift towards voluntary support and care that emphasises social support and care away from compulsory treatment in hospitals that emphasise medical treatment.

However, we strongly disagree with the Review's proposed solution to place duties in law for NHS Boards, Health & Social Care Partnerships, and local authorities to provide "secure support centres" for people with learning disabilities for *"people who need to be detained and for people who need to be detained and given compulsory support, care or treatment."*³⁸

³⁸ The independent review of Learning Disability and Autism, Stage 3 of the review (2019)

We also oppose the proposal of a presumption in law of placement in a specialist health and social care environment for people with learning disabilities whose rights are limited and completely disagree that people with learning disabilities should have access to these centres without mental illness.

When someone with a learning disability has an acute mental health problem, we think they have a right to access quality personalised mental health services and be covered by existing Mental Health legislation. The Review says, “Although some people will come to emergency psychiatric services, we think it will be important for most people that they do not stay in general psychiatric services.”³⁹ We would like further explanation of the evidence base for this.

The Review cites the European Court of Human Rights which has indicated that support, care and treatment must meet the individual need of people who are detained for mental health reasons. We agree with this. But we strongly disagree that secure support centres, on the basis of diagnosis is the way to achieve this.

The evidence suggests that when people with learning disabilities enter from Assessment and Treatment Units (ATUs) they often experience delayed discharge remaining in the hospital when there is no clinical need for them to be there⁴⁰. The 2018 mental health and learning disability inpatient Census showed that 28% of patients in learning disability wards were delayed discharges⁴¹. The Scottish Government’s report on Out-of-Area Placement and Delayed Discharge for People with Learning Disabilities and Complex Needs found that the main reasons given by HSCPs for delayed discharges were lack of service provision and lack of suitable accommodation⁴².

³⁹ The independent review of Learning Disability and Autism, Stage 3 of the review (2019)

⁴⁰ Scottish Government (2018) Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs

⁴¹ Mental Health & Learning Disability Inpatient Census and Out of Scotland NHS Placements Census, 2018.

⁴² Coming Home A Report on Out-of Area Placements and Delayed Discharge for people with Learning Disabilities and Complex Needs, Scottish Government (2018)

SCLD does not believe there is any justification or merit in creating further places of detention for people with learning disabilities. The Review suggests that secure support centres would run in parallel to other mental health services would be run by Health & Social Care Partnerships and led by social work or social care professionals with input by health professionals. It says they could be commissioned by Health & Social Care Partnerships within the third sector or the independent sector. We are completely opposed to these suggestions and believe this opens the door to privately run units for people with learning disabilities.

There is clear evidence that in such segregated settings individuals become invisible and vulnerable to mistreatment and abuse⁴³. Additionally, a recent report⁴⁴ by the Care Quality Commission in England reports that 14 independent mental health or learning disability hospitals that admit people with a learning disability or autism were rated as inadequate and put into special measure from October 2018 to September 2019. It found that too many people with a learning disability or autism are in hospital because of a lack of local, intensive community services.

The Review provides little detail on the nature and purpose of “safe spaces” beyond places where people could get support, care and treatment on a voluntary basis at times of crisis. It says these would be designed to meet the needs of people with a learning disability. We would like to see considerably more detail about what this would look like in practice.

SCLD believes that more and better community services are needed to help people avoid crisis situations. For many hospital stays are prolonged because of delays in setting up the package of care they need after discharge. There is a clear need for

⁴³ Department of Health (2012) *Transforming care: A National response to Winterbourne View Hospital*

⁴⁴ CareQuality Commission (2019) *The state of health care and adult social care in England 2018/2019*.

further investment in preventative services, early-stage or low-level support, and community-based health and social care services. In our view, resources could be better deployed in increased availability and accessibility mental health crisis services and wider provision of community mental health nursing.

How professionals make decisions

We suggest that Scotland should make changes to move closer to compliance with the right to liberty and security. This is another key right in the Convention on the Rights of Persons with Disabilities.

We suggest that Scotland is not yet ready to end all detention on the basis of disability, or all compulsory treatment, in a safe way.

We suggest that human rights assessments should be the basis for all professional decision making for autistic people and people with learning disability.

We suggest new roles for a broad range of professionals.

7. Professional Decision Making

SCLD believe that the Review's proposals on the right to liberty and security do not go far enough. We recognise that there are different views in international human rights as to whether and under what criteria detention and compulsory treatment is ever permissible.⁴⁵ And we agree with the review that there are times when a person's rights may have to be limited, to protect the person's overall rights.

⁴⁵ Gurbai, Sandor and Martin, Wayne (2018) Is Involuntary Placement and Non-Consensual treatment Ever Compliant with UN Human Rights Standards?

However, we are extremely disappointed that the review suggests Scotland is not ready to end detention and compulsory treatment on the basis of disability.

The Convention on the Rights of Persons with Disabilities (UNCRPD) states clearly that deprivation of liberty based on the existence of a disability is contrary to international human rights law, is intrinsically discriminatory, and is therefore unlawful. The UK's review by the UNCRPD Committee in 2017 recommended that the State party: "Repeal legislation and practices that authorize non-consensual involuntary, compulsory treatment and detention of persons with disabilities on the basis of actual or perceived impairment"

Furthermore, there is clear tension between involuntary placement/treatment and the right to legal capacity. The UNCRPD Committee states that detention of persons with disabilities in institutions against their will (either without their consent or based on the consent of a substitute decision-maker) constitutes arbitrary deprivation of liberty and violate both Article 12 (Equal recognition before the law) and Article 14 (Liberty and security of the person) of the UNCRPD.⁴⁶

Stavert (2018) explains, however, that equal enjoyment of human rights without discrimination does not mean that rights can never be denied or limited. It means that any denial or limitation must be based on the same criteria for all persons and must not be justified on the basis of a person's disability".⁴⁷

It is SCLD's position, therefore, that equal recognition before the law, by definition, must prohibit involuntary interventions such as detention or compulsory treatment on the basis of a person's learning disability. We recognise that there are circumstances in which individuals may be unable to protect themselves from risk and harm to themselves and others. However, we are clear that any criteria in law

⁴⁶ CRPD Committee (2014) General Comment No.1

⁴⁷ Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD in Scotland

that restricts the rights of people with learning disabilities must be non-discriminatory and therefore applicable to everyone.

Therefore, we fundamentally disagree with the Review's proposal to create new and separate criteria for detention and compulsory treatment for people with learning disabilities. It is proposed that the new criterion for this involuntary treatment would become 'disability' rather than a mental disorder. Someone diagnosed by a psychiatrist or clinical psychologist to have an intellectual impairment and assessed to be "experiencing stress or distress to the extent that the person is of 'unsound mind'" would be considered to be experiencing 'intellectual disability'.

We consider this to be at least as discriminatory, and therefore unlawful and non-compliant with the UNCRPD, as the current criteria in which learning disability is included as a mental disorder.

The proposed criteria also extends the justification for involuntary intervention beyond the availability of medical treatment to circumstances where support, care and treatment is available to reduce the person's disability. We are concerned that this could lead to more people with learning disabilities being detained not for mental health reasons but due to behaviour that is perceived to be challenging. As the Millan review's report⁴⁸ observed: 'Evidence of the effectiveness of interventions which are authorised under mental health law is limited. Challenging behaviour may reflect inappropriate or inadequate services, and the answer should be to provide the right services, rather than place the client under greater constraints.'

We agree with the Review's proposals that any professional decisions that limit a person's rights must be proportionate and necessary and protect a person's overall rights. The review says:

"A Mental Health Officer could do a human rights assessment, based on the persons view and on the person's statement of rights, will and preference if they have one.

⁴⁸ Millan, B (2001) Report on the Review of the Mental Health (Scotland) Act 1984

*The assessment might include information from unpaid carers and information from professionals.*⁴⁹

We think there is merit in the idea of human rights assessment to ensure that any actions taken by professionals which are contrary to person's rights, will and preference are necessary and proportionate. However, there is an absence of any detailed case studies to providing example of these. We think further explanation is required as to their exact nature and how they would operate in practice.

It will be vital that there a stringent safeguard to avoid conflict of interest and undue influence. It is also essential that even at times of crisis support for decision making is taken just as seriously to ensure that people's rights, will and preferences are respected. We are unsure as to whether a mental health officer will be best placed to carry out a human rights assessment and suggest that consideration be given to the role of Human Rights Officer.

Furthermore, for these to apply in a non-discriminatory way requires human rights assessment to be adopted universally within mental health where decisions are taken to restrict rights, not only where people with learning disabilities are concerned.

It is paramount people with a learning disability have a right to challenge decisions where a professional does not agree with their will and preferences for support, care and treatment. We agree with the Review that people must have the right to challenge decisions to restrict rights, to take any human rights breaches to the Mental Health Tribunal and to notify the Mental Welfare Commission when any statement of rights, will and preference was not complied with, in addition to duties on professionals to report this.

We would like to see the process by which someone could do this outlined in greater detail. It will be essential that people with learning disabilities are aware of their rights and have support and information to access mechanisms by which they can

⁴⁹ [The independent review of Learning Disability and Autism, Stage 3 of the review \(2019\)](#)

seek readdress when these are not upheld. We welcome the Review's proposals for accessible communication standards and agree that people with learning disabilities should be central to developing these.

We welcome the proposal people with learning disabilities should be involved in the training of professionals but believe this would need to take place in a genuinely co-productive environment to mitigate the inherent power imbalances.

How decisions are monitored

We think that Scotland needs mental health law and services based on human rights. We think that autistic people and people with learning disability should be routinely involved in developing, implementing and monitoring the law and services.

We suggest that the Mental Welfare Commission for Scotland and the Mental Health Tribunal for Scotland should be more authority to protect the rights of autistic people and people with learning disability.

We make a range of suggestions on how human rights should be monitored.

8. Monitoring of decision making

We agree with the Review's proposals that people with learning disability should be routinely involved in developing, implementing and monitoring mental health, policy and practice. We also agree with the Review's proposals that organisations run by and for people with learning disabilities must have the resources they need to be able to do this effectively. We believe this must include support for self-advocacy groups to increase representation of people with learning disabilities with profound and multiple learning disabilities. We also believe, however, that this involvement needs

to be wider and that people with learning disabilities and their organisations must have a greater role in the monitoring of Scotland's compliance with the UNCRPD.

The Scottish Government committed to giving effect to UNCRPD rights in its *A Fairer Scotland for Disabled People* (2016)⁵⁰. We are aware that for many people with learning disabilities the advancement and realisation of their human rights has been particularly challenging due to a complex interplay of societal barriers and institutional discrimination.⁵¹ Despite many of the rights within the UNCRPD being bolstered by the public sector duty on socio-economic inequalities (which came into force in Scotland in April 2018)⁵², for many people with learning disabilities there is a feeling that existing legislation fails them. Therefore, we believe it is essential that people with learning disabilities have access to support to become more aware of their human rights and crucially to be able realise them. This must also be accompanied by development of mechanisms of complaint and enforcement where human rights are not being met and responsibilities are not being fulfilled by duty bearers.

In the mental health context, we agree that there should be standards for dignity, accessibility, equality and non-discrimination based directly on the EHRC and UNCRPD. We think that national equality and human rights bodies should have a role in scrutinising these standards. We also agree with the Review's proposal that the Mental Welfare Commission should have the authority to enforce these human rights-based standards for mental health services for people with learning disability and should act to ensure that each person's human rights are promoted, protected and fulfilled.

⁵⁰ Scottish Government (2016) *A Fairer Deal for Disabled People*

⁵¹ SCLD (2018) *Children's Rights: Consultation on incorporating the United Nations Convention on the Rights of the Child into our domestic law in Scotland*

⁵² Scottish Government (2018) *Fairer Scotland Duty: interim guidance for public bodies*

We believe that equality and human rights impact assessments should be central to this process. These assessments should take a holistic approach to human rights and give sufficient space to addressing the needs and aspirations of people with learning disabilities and the intersections of disability, race, socio-economic status, gender, and sexuality. It is critical that these assessments are taken seriously and this requires assessors with competency and relevant experience in equality and human rights.

We agree that the Mental Welfare Commission should set standards for the use of support, care and treatment, supported decision making and independent advocacy in mental health services. However, we are clear that the Mental Welfare Commission and the Mental Health Tribunal should only have a role for monitoring people with learning disabilities when they have severe mental health problems and are subject to the Mental Health Act on that basis. Therefore, we disagree with the proposals in the Review that the Commission should have the authority to intervene in *'any matter that seems to contribute to a person's disability'*⁵³ e.g. inadequate support or failure to provide housing. We think this conflates disability with mental health and that it would not be appropriate for the Mental Welfare Commission to have oversight over these matters.

The Review proposes that the Mental Welfare Commission would set standards for restraint, seclusion and restriction to liberty. We believe the use of these practices must be strictly limited and rigorously monitored. Furthermore, we believe that there must be consistency in their use across mental health, education, social care and criminal justice. In our view, this requires national human rights based standards and monitoring of these practices across all settings. Furthermore, it is imperative that

⁵³ [The independent review of Learning Disability and Autism, Stage 3 of the review \(2019\)](#)

these standards align with the on-going work to incorporate the UNCRC into Scots law.

We support the monitoring of prescribing of psychotropic medication for people with learning disabilities as well as the monitoring of authorisation for compulsory treatment. However, we believe this monitoring must also include the extent of 'off-label prescribing' e.g. drugs being used outwith the context for which they are licenced. We believe the Mental Welfare Commission are well placed to undertake this.

We agree that the Mental Health Tribunal system must become more accessible for people with learning disabilities. We support the Review's proposals to provide papers in advance in an accessible format and agree that tribunal decisions need to be communicated more clearly. We see a clear role for supported decision making in helping facilitating greater engagement in the tribunal process by people with learning disabilities. We also believe the appeals process must become more accessible and easier to navigate for people with learning disabilities. This should be supported by a range of communication tools including Easy Ready Documents, Talking Mats and augmentative communication tools including Eye Gaze. Particular attention should be given to how these processes can be made more accessible to people with profound and multiple learning disabilities.

Offenders

We suggest changes to make the criminal justice system fairer for autistic people and people with learning disability.

We suggest that Scotland uses 'intermediaries' to support suspects and defendants who have communication impairment.

We suggest a change to how disability is understood in criminal law. This change could make it possible for person to be held responsible for an offence, but also to have adapted consequences that take account of the person's disability.

We suggest that punishment, treatment and support to stop offending should be clearly separated out in law for autistic offenders and offenders with learning disability.

We suggest that punishment should not be longer for these offenders than for any other offenders.

Where support, care and treatment happens for offenders

We suggest that rehabilitation should usually happen in the community, for offences that would usually lead to community rehabilitation for anyone else.

We suggest that offenders should usually be given support, care or treatment in the community or in rehabilitation centres, not in hospitals.

We suggest that prison should only be used for autistic offenders or offenders with learning disability when it is specially designed or adapted to meet the person's needs.

9. Support care and treatment for offenders

We agree with the Review's proposals to make the criminal justice and legal system more accessible to people with learning disabilities. We believe this is a critical element to ensuring that people with learning disabilities have effective access to justice on an equal basis with others. This includes the right to a fair trial in court.

It is crucial, therefore, that people with learning disabilities are offered the additional and reasonable adjustments they need to ensure a fair and just process. We understand, however, the argument presented in the Review that “it is not enough for a person to express their will and preferences to take part meaningfully in trial. The person must also be able to understand the charges, tell their lawyer what to do, follow the process, and give evidence in their own defence”.

Therefore, we accept that in some instances there may be insurmountable barriers to ensuring a fair and just trial and this may require a judge to declare that someone is unfit to stand trial. To do this fairly, we think there is merit in an approach which considers the person’s rights, and balances these against whether it is proportionate to make the person take part in a trial. However, it is critical that any criteria are applied uniformly and in a non-discriminatory way.

More generally, individuals with learning disabilities commonly experience communication difficulties and other barriers that impact their ability to understand and communicate effectively in the criminal justice system⁵⁴. Research by the Equality and Human Rights Commission (EHRC) in 2017⁵⁵ highlighted there is no consistent method in the criminal justice system for assessing requirements for additional support. The Scottish Human Rights Commission (SHRC)⁵⁶ found that police officers tend to rely on their own experience to make a subjective assessment about whether someone has a learning disability and requires additional support.

Therefore, we support the Review’s proposal for ‘intermediaries’, to be made available for people with learning disabilities who come into the criminal justice system as suspects or defendants. The intermediary (speech and language therapists or social workers) would meet with person before the police interviews to assess any

⁵⁴ SOLD (2016) [Improving Support for people with learning disabilities from assert to court](#)

⁵⁵ EHRC (2017) [Experiences of people with a learning disability in the Scottish criminal justice system](#)

⁵⁶ SHRC (2017) [Disability Rights in Scotland](#)

communications barriers and requirements for additional support. The intermediary would then provide a report to the police and court.

The intermediary would also help a person understand information and support them with their communication as well advise and inform the court if the person is having difficulty understanding the questions. The Supporting Offenders with Learning Disabilities (SOLD) Network's user group⁵⁷ has emphasised that this kind of support requires time to prepare and an in-depth understanding of communication needs as well mutual trust.

We suggest there could also be a role for the intermediary to provide support to ensure that the person understands their rights, the implication of their answers they give and is not unduly distressed. We agree with the Review that to prevent discrimination, the intermediary system should be for everyone who is charged with a crime or who is prosecuted for a crime and who needs support with their communication.

We believe a range of disposals should be available to the courts to take account of any reasons for offending, mitigating factors and, if custodial sentences are thought to be necessary, take account of a person's learning disability and communication needs and these can be accommodated. However, we do not agree that the law clearly should allow for offenders with disabilities to be treated 'more favourably' than offender without a learning disability.

We think there is merit in the proposal to separate out punishment, support to stop offending, and support care and treatment in court disposals. It is critical that risk assessment tools and practices, and decisions based on these are monitored to prevent any discrimination on the basis of disability.

At present, it is possible for an offender with learning disability to be detained or restricted in forensic wards, units or hospitals for longer than another person would

⁵⁷ SOLD (2017) [Improving support for the accused person with a learning disability in Police Custody](#)

spend in prison for a similar offence. We agree with the proposals for a presumption that detention will not be in these settings in most cases.

It is vital, however, to ensure that people with learning disabilities have a safe experience while serving custodial sentences. We agree that this requires environments where people are protected from violence and abuse and have access to the appropriate support, care, treatment.

However, we do not believe that detention centres for people with learning disabilities will be an effective way of rehabilitating people. In our view, any offender including someone with learning disabilities should be sentenced in a way that will help with their rehabilitation and encourage them not to reoffend.

Therefore, we agree with proposals for support in custody to help people to stop offending behaviour such as social supports, education programmes and psychological interventions. And we are strongly in favour of the universal use of community based sentences where these are appropriate.

What this means for the law

We suggest that autism and learning disability should no longer be defined as 'mental disorders' in Scotland's Mental Health Act.

We suggest that Scotland develops a new law to give 'positive rights' for support, care and treatment to autistic people and people with learning disability.

We give a summary of the changes that we are suggesting for criminal law.

We suggest how Scotland might prepare to end detention on the basis of disability, and to end compulsory treatment, at some time in the future.

10. Legislative change

We agree with the Review's proposals that learning disability should no longer be considered as a 'mental disorder' under the Mental Health (Care and Treatment) (Scotland) Act 2003. We also agree with the Review that in removing learning disability from the term 'mental disorder' people with learning disabilities should not lose rights that they currently have in other laws. At present 'mental disorder' appears in around 25 acts of the Scottish parliaments and, in our view, legislative change will be required to protect existing rights.

Additionally, we strongly agree of the Review's intention to ensure people with learning disabilities have equal standing before the law, with the support they need to make full use of their legal capacity and have access to the support, care and treatment they require. However, we are have concerns that the legislative change proposed by the Review continues to view learning disability through a 'medical model' and that elements within it may lead to unintended consequences that increase inequalities and lead to poorer outcomes for people with learning disabilities.

In particular, we have concerns that the Review's proposals will create a separate mental health system for people with learning disabilities which continues to permit detention and involuntary treatment on the basis of a person's learning disability alone. In our view, this would continue to limit the rights of people with learning disabilities in a discriminatory fashion, and may increase instances of non-consensual interventions. We have concerns that such interventions, which place people in segregated settings on the basis of their diagnosis, risk making individuals 'invisible' and vulnerable to mistreatment and abuse.

Therefore, we have serious reservations about the Review's proposals for a separate law for people with learning disabilities. In particular one which places duties to

provide mental health support, care and treatment for all people learning disabilities on the basis of their learning disability diagnosis. In our view, people with learning disabilities who require mental health services should be entitled to high quality, accessible and personalised support, care and treatment under existing or reframed legislation which is applicable to everyone. We understand that there may be occasions when people with learning disabilities are detained for care and treatment but the grounds upon which this is lawful must be “de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis”⁵⁸.

Furthermore, we believe that transformational change is necessary to create the culture and environment which enables people with learning disabilities to realise their human rights on an equal basis with others. People with learning disabilities should enjoy full and active participation in all parts of life. They should not be excluded and viewed only as individuals who receive treatment and care. In our view, this is likely to require legislative as well as non-legislative measures, however, at present we remain to be convinced that separate legislation for people with learning disabilities will achieve that.

Currently, there is a considerable legal and policy framework that seeks to drive change to improve the outcomes for people with learning disabilities including *The Keys to life, A Fairer Scotland for Disabled People*, the Human Rights Act 1998, the Equalities Act 2010, as well as commitments to the UNCRPD. In our view, for people with learning disabilities to realise their human rights on an equal basis with others they must be empowered to understand and claim their rights as equal citizens. There must also be a much greater focus on accountability of duty bearers and on access to redress when rights are not met.

⁵⁸ Gurbai, Sandor and Martin, Wayne (2018) *Is Involuntary Placement and Non-Consensual treatment Ever Compliant with UN Human Rights Standards?*

In 2017, the Mental Welfare Commission for Scotland and Centre for Mental Health and Capacity Law (Edinburgh Napier University) proposed, with respect to Scotland's mental health and capacity law, that: *'There should be 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.'*⁵⁹

We believe that people with learning disabilities must be part of this 'coherent and non-discriminatory legislative framework', rather than being isolated in a separate law. However, we recognise that this presents fundamental challenges and poses difficult questions around concepts of autonomy, risk and capacity assessments. However, we think there is significant merit the Review's proposals for human rights assessments in this context and believe their application should be considered more widely in the context of incapacity law.

To conclude, SCLD believes, that the findings from this review alongside the review of Adults with Incapacity (Scotland) Act 2000 and The Mental Health (Care and Treatment) (Scotland) Act 2003 provide a definitive opportunity to transform the lives of people with learning disabilities in Scotland through long-term re-alignment of the current legislative framework that impacts their lives. We believe, that this transformation should be underpinned by a wider debate on the role of the UNCRPD in achieving whole-systems culture change for people with learning disabilities

⁵⁹ Stavert, J (2018) Paradigm shift or Paradigm Paralysis? Mental Health and Capacity Law and Implementing the CRPD in Scotland

Appendix A

Introduction

SCLD

The Scottish Commission for Learning Disability (SCLD) welcomes the opportunity to respond to this important consultation. SCLD is an independent charitable organisation and strategic partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The Keys to life* (2013)⁶⁰. The strategy defines a learning disability as a significant, lifelong, condition that started before adulthood, which affects development and means individuals need help to understand information, learn skills, and cope independently. SCLD is committed to finding new and better ways to improve the lives of people with learning disabilities and is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

The consultation

The consultation is to give feedback on proposals for changes to the current Mental Health (Care and Treatment) (Scotland) Act 2003. The review team have written a number of proposed changes which they believe will make the current law better for people with learning disabilities and autistic people. The proposals are designed to make sure that Scotland's mental health act matches up with other laws and regulations like the European Convention on Human Rights and the United Nations Convention on the Rights of Person's with Disabilities. The review team are asking

⁶⁰ [*The keys to life* \(2013\)](#)

for feedback on their ideas to make it better. After looking at the feedback they get to their ideas the review team will make some recommendations to the Scottish Government.

The Focus Group

SCLD held a focus group to hear the views and experiences of people with learning disabilities. In attendance were, 4 people with learning disabilities, 1 autistic person, 1 parent and 3 supporters.

The focus group focussed on the following areas:

- The term Mental Disorder
- Support for Making Decisions
- Special Services for people with learning disabilities and autistic people
- New laws for people with learning disabilities and autistic people

The discussion was facilitated by two members of SCLD staff, the focus group was mostly discussion with some interactive examples used to explain concepts like supported decision making. A graphic facilitator recorded some of the conversation and drew some images that helped to explain

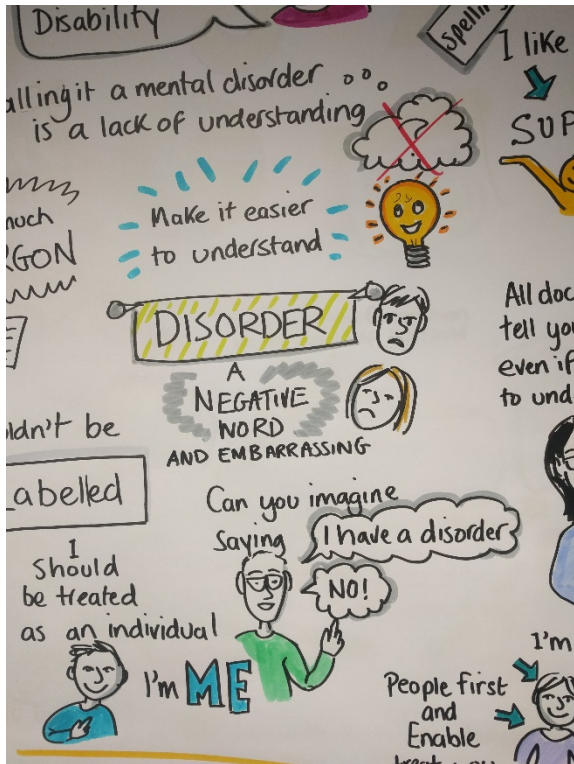
About this report

This report gives a summary of the conversations at the focus group held on Friday 4th October in The Grassmarket Project, Edinburgh. These will be used to help to inform SCLD's response to the consultation. It is also provided separately for the focus group attendees.

This report does not form a view on the questions in the consultation it is simply a report on the conversations and feedback received from the focus group participants. All graphics and quotes used in this report are from this focus group.

The Term Mental Disorder

All of the attendees agreed that they did not like the term mental disorder and said they would welcome this change.



It was felt to be a very negative word which people did not want to have associated with themselves. It was said to be embarrassing and not a term that anyone in attendance would want to use.

“I feel the word disorder is negative. They should not use that terminology...it can be embarrassing for people with mental health issues and learning disabilities”.

Comments were made that to have learning disabilities defined in the same way as mental ill health showed a lack of understanding of what a learning disability is and how it effects a person. It was noted that a person is born with a learning disability, it is not something that is developed later in life. It also cannot be treated and cured but a person can be supported.



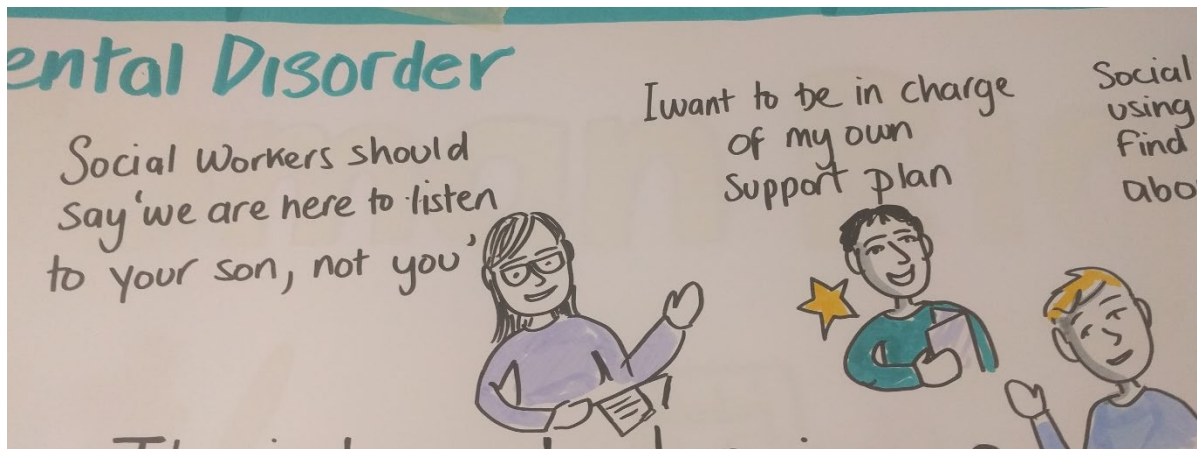
The group discussed terminology and the idea of labelling. No one in the group wanted to be labelled but did identify that there are things they need some support with and that sometimes they needed things to be done in a certain way, like information to be provided in a format they can understand. It was discussed that in order for people to get the support they need professionals need to treat everyone as an individual and to try to understand and support each individual with what they need support with.

“I don't want to be seen as disabled, I'd like to be seen as normal – seen as an individual”

“I like the word support, what do you need support with, like how I needed support to get here.”

“I was treated differently because they didn't understand me”

Support for Making Decisions



A large part of the conversation at the focus group was about decision making. Those in attendance had a range of experiences of making decisions about their day today lives. 1 had no family involvement and was under local authority guardianship. A support worker reported that as the guardian does not know them very well they make sure to talk to the support workers and find out as much as they can before making any decisions about care and support. 3 of the people at the focus group said that they had a lot of involvement from their families when it came to making decisions.

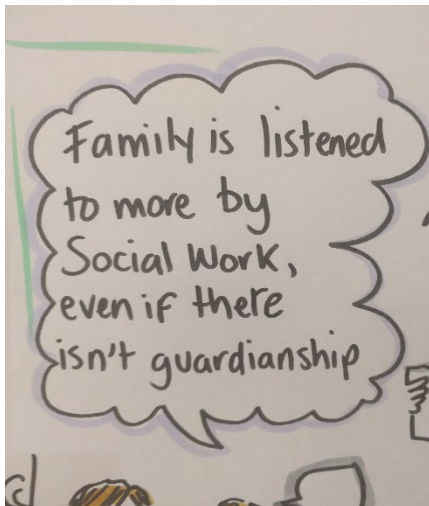


A number of examples were given of when a person had made a decision with support from some of their family members when other members of the family had been trying to get them to choose something different. These were big life decisions like where they were going to live, in one case they had been to

see a solicitor to ensure that their wishes could not be overruled by the family.



All 3 said that sometimes their families did not want the same things as them and they could be overprotective.



It was often felt that social workers, doctors and other professionals listened to families more than they did to the person who the decision was about. On the other hand a parent who was at the focus group said that she they thought that often decisions are made without talking to the person's family.

The people at the focus group liked the idea of having an advocate who would be able to get to know them and could help to ensure that their rights, wills and preferences would be heard and taken into account. People talked about how difficult it can be to have to keep telling different people the same things about the support they need.

“its all about choice”

“How would they know what to decide for me, if they don't see me”

“It is hard to explain over and over again”

“My Mum gets into the social workers head”

Special Services

During the focus group we talked about the suggestion that there should be separate services for people with learning disabilities and autistic people. This would mean that people would be treated in different hospitals away from people who do not have learning disabilities or autism. The people at the focus group did not agree with this idea. They all agreed that they wanted to be treated in the same hospitals as everybody else. People said that it is important that people who work in these hospitals can understand what kind of support an autistic person or a person with a learning disability might need.

People strongly felt that they did not want to have separate specialist hospitals.

New Law

The people at the focus group welcomed some of the suggestions for the new law for people with learning disabilities. The group were supportive of the idea that everyone would be able to have access to advocacy. They thought it would be good

if people with learning disabilities should always have access to an advocate at points of transitions around leaving school or moving to college.

The group felt that having to tell someone over and over about yourself, especially when new people came into roles was unhelpful.



The idea of health checks worried some people as they thought that if you had to go for a health check they might find something wrong with you. People were worried that if these came under the law then it could allow treatment to be forced.

Thank you to everyone who took the time to come to the focus group for sharing your thoughts and opinions with us.

Contact us

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For information on Scotland's Learning Disability Strategy *The Keys to life*, visit: www.keystolife.info

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