



Consultation Response

Clinical Pathways and Guidance for Healthcare Professionals Working to Support Adults who Present Having Experienced Rape or Sexual Assault in Scotland

The Scottish Commission for
Learning Disability
January 2019



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 life¹. The strategy defines a learning disability as a significant, lifelong, condition that starts 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 aim of this response is to support the Scottish Government in the development and delivery of policy through sharing knowledge and providing practical solutions to policy based challenges in line with SCLD's strategic plan 2017-21.

With regards to the 'Clinical Pathways and Guidance for Healthcare Professionals Working to Support Adults who present having experienced Sexual Assault or Rape', SCLD have three central areas of concern which relate to questions in section 4 and 6 in this consultation document. SCLD's three primary areas of concern are,

- 1. A lack of information about the experience of people with learning disabilities with regard to sexual assault and rape**
- 2. A lack of information on the human rights and sexual autonomy of people with learning disabilities**
- 3. Ensuring the appropriate balance of human rights and risk in establishing informed consent**

¹ [The keys to life](#)

SCLD discusses each of these areas of concern in detail below. Following this, SCLD makes a number of recommendations for how the guidance can address these issues and work to ensure people with learning disabilities have access to appropriate service provision, equitable to the experience of the wider population.

1. A lack of information about the experience of people with learning disabilities with regard to sexual assault and rape

Section 6: Q.1 Are there any key areas of research missing?

Do you have any comments or additions on topics which are not covered in previous sections? Please be specific in your reasons and include any resources or references we should consider.

SCLD believes there is a significant research gap within the prevalence of sexual violence among individuals who have a learning disability. While the guidance addresses socio-economic inequalities (race, sexuality, and gender), there is a significant omission of disability and, in particular, learning disability. It is important that the rights of people with a learning disability to enjoy and maintain healthy relationships, including sexual relationships, are also recognised.

In order that people with learning disabilities can enjoy safe relationships there is a need to provide equitable provision of sexual health and crisis services, in line with the rest of the population. Central to achieving this is ensuring the particular needs of people with learning disabilities are reflected in this guidance. This should include

disabled women's experiences of violence (including sexual violence) discussed in Boltzmann (2014)² and the role institutionalisation has played in this.

The impact of long term disempowerment of people with learning disabilities has been well documented in research from the late 20th century onward. This is demonstrated in Tharinger et al (1990)³ , who cited Anderson (1982)⁴, and stated that people with learning disabilities were often subject to the will and wishes of those around them. As they stated,

“Compliance with caregivers often is overemphasised at the expense of lessons in assertiveness or independence.”

(Tharinger; 1990, p.304)

This is supported by Enable (2009)⁵ who identified a lack of opportunity to develop independence as a contributory factor to sexual abuse. In addition, qualitative research carried out with serial sex offenders in Canada found that 69% of offenders indicated that person's perceived submissiveness or vulnerability impacted their decision to assault them⁶.

In understanding people with learning disabilities' exclusion and historic disempowerment, it is critical that particular focus is given to people with learning disabilities in this guidance. This focus should illustrate that rape and sexual assault does impact people with learning disabilities and that this is not a small scale issue. In SCLD's report, 'Safe and Health Relationships: Empowering & Supporting People

² [Boltzmann \(2014\)](#)

³ [Tharinger, Horton, & Millea \(1990\)](#)

⁴ [Anderson \(1982\)](#)

⁵ [Enable \(2009\)](#)

⁶ [Beauregard, Rossmo & Proulx \(2007\)](#)

with Learning Disabilities through Education⁷ evidence was drawn from McCarthy 2014⁸ and 2016⁹ which highlighted people learning disabilities increased risk of experiencing sexual violence, discriminatory attitudes and abuse.

However, the guidance should be clear that learning disability and sexual assault are not inextricably linked. Without making this clear, there is the potential to perpetuate a protectionist and deficit-focused culture. Instead, the guidance should be clear that disability does not cause or lead to rape and sexual assault and should be cautious of a subconscious dialogue of victim blame. When addressing disability, the guidance should give balance and consideration to ensure an asset-based model of support for people with learning disabilities, which avoids unnecessary restrictions on liberty and rights.

In considering the complexity of this area, SCLD would welcome the opportunity to support The Scottish Government in drafting this section of the guidance. SCLD would also welcome input from The Mental Welfare Commission on this.

SCLD believes that further up to date knowledge on rape and sexual assault and learning disability would be of significant benefit. At present, there is a substantial gap in knowledge around the existing picture of reported sexual offenses committed against people with learning disabilities in Scotland.

⁷ [SCLD \(2018\)](#)

⁸ [McCarthy \(2014\)](#)

⁹ [McCarthy, Hunt & Milne-Skillman \(2016\)](#)

2. A lack of information on the human rights and sexual autonomy of people with learning disabilities

For SCLD, it is critical that those providing frontline crisis support understand the human rights of people with learning disabilities and the delicate balance between this and protection. This should help to ensure that professionals do not violate these rights through a culture of over protectionism.

This overprotection of people with learning disabilities with regards to sexual autonomy has been well documented. David Hingsburger¹⁰ provides an excellent illustration of what he refers to as the 'prison of protection'. In this prison, a person viewed as vulnerable is imprisoned by four walls. These four walls are: society, decision making, sexual information and relationships. Hingsberger writes:

"The prison of protection is built of kindness. When we as service providers see someone as being 'vulnerable' because of who they are we become protectors. There are four walls to the prison. The walls are built to protect the person, who is seen as vulnerability encased in flesh."

(David Hingsburger; 1995, p.16)

Examples of over protection of people with learning disabilities have been clearly demonstrated in research. This is particularly evident in Hollomotz (2008)¹¹ research examining people with learning disabilities opportunities for privacy to pursue romantic relationships in residential settings. Participants in this study spoke about having the locks on their bedroom door removed from their doors to discourage them from sexual relationships.

¹⁰ [Hingsburger \(1952\)](#)

¹¹ [Hollomotz \(2009\)](#)

Given the context of historic and ongoing restrictions on people with learning disabilities' sexual autonomy, the guidance should address the complex interrelationship between protections and rights. SCLD asks that the guidance outlines people with learning disabilities' rights to sexual relationships in line with Article 8 of The Human Rights (1998)¹², the right to a Private and Family Life. Alongside this the guidance should outline the duty the UN Convention on the Rights of Persons with Disabilities (2009)¹³ places on the state to ensure disabled people are appropriately protected from exploitation and abuse. The matter of protection and rights should be addressed in the section on establishing informed consent with regard to forensic examinations.

3. Ensuring Human Rights in Informed Consent

5. Do you agree with the guidance in this pathway on informed consent?

6. Do you agree with the guidance in this pathway on incapacity?

Hingsburger's¹⁴ prison of protectionism is of particular relevance when establishing informed consent for treatment and forensic medical examination. This is partially addressed in the consultation document, where it states:

"In order for consent to be 'valid,' the individual must have been given sufficient, accurate and relevant information"

(The Scottish Government; 2018, p.48)¹⁵

¹² [The Human Rights Act \(1998\)](#)

¹³ [UN Convention on the Rights of Persons with Disabilities \(2009\)](#)

¹⁴ [Hingsburger \(1952\)](#)

¹⁵ [The Scottish Government \(2018\)](#)

However, SCLD believes that with regard to people with learning disabilities, healthcare professionals need to be supported to break habits of well-intentioned, over-protection of people deemed vulnerable. This relates to the idea of professional judgment and what information is considered to be necessary to provide to a patient. The consultation document correctly identifies *Montgomery V Lanarkshire*¹⁶ as setting a new legal precedent in Scotland. This judgment asked professionals to move away from the clinical judgment of what a person should be told to instead telling the patient what they would want to know.

For people with learning disabilities, the prison of protectionism presents an additional barrier to receiving information. Due to a perception of vulnerability, professionals shield individuals with learning disabilities from information. For example, people with learning disabilities' systemic exclusion from sex education¹⁷.

Shielding people with learning disabilities from information deemed 'unsuitable' denies them the opportunity to make informed decisions. Without the provision of accessible information which is articulated and understood, it is difficult to ensure a person has come to their decision based on an understanding of the outcome. Even when a professional is not actively withholding information from an individual, challenges can occur as a result of unclear and non-explicit communication. An example of this is given below:

A person with a learning disability has been sexually assaulted. This person reports the crime but does not understand the need for a forensic examination in successfully bringing criminal charges against the accused. The medical professional warns the person that the forensic examination may be 'unpleasant'. However, the professional does not explain the legal need for an examination in proving the guilt

¹⁶ [Chan, et al \(2017\)](#)

¹⁷ [SCLD \(2018\)](#)

of the accused. Because the person has not been told about why the examination is needed and they are told it is 'unpleasant' they decide not to have it. This directly impacts their ability to bring a criminal case against the accused.

Individuals should be able to accept or refuse treatment and examination based on an understanding of the outcomes of their choice. People with learning disabilities may require support to help them reach an understanding and a decision. This support can be provided by an advocate or support worker. However in cases where this provision is not made available it is the responsibility of those conducting the examination to ensure:

- The person has received all the necessary information
- The person is given the information in a way they understand
- The person is given the opportunity to ask any questions

Where the above is not provided, information can be said to be presented to an individual in a way which creates a “framing effect”¹⁸. In Chan et al (2017)¹⁹ analysis of the Montgomery Case, the framing effect and its impact are discussed. The authors, state:

“...the communication process has a strong influence on how patients understand, remember, and evaluate information – all of which are essential to informed consent. The doctor’s role is to ensure that relevant information is presented to enable the patient to use it meaningfully.”

(Chan et al; 2017, p.2)

¹⁸ [Chan, et al \(2017\)](#)

¹⁹ [Chan, et al \(2017\)](#)

The role of communication in framing an individual's decision making is amplified when a patient is a person with a learning disability. This was discussed in Ali et al's (2013)²⁰ study of the barriers and discrimination that people with learning disabilities experience in accessing health services in England. In this study, researchers identified that people with learning disabilities experienced significant challenges in communication with health professionals. This included:

- Staff failing to adapt their communication style
- Giving too much information
- Not giving the person time to process information

The researchers also stated that a lack of confidence could mean an individual with a learning disability was unable to put across their views. A lack of confidence experienced by people with learning disabilities is likely to be heightened when encountering a person in a position of authority.

This kind of power imbalance has been demonstrated across research, as identified in Joseph-Wilson et al (2014)²¹ systemic review of the patient-doctor joint decision making. This study identified 44 existing studies and examined them for emergent themes. One theme identified was patients handing over all power to their doctor in the belief they know what is best or because they felt overpowered by the views of the professional.

This power imbalance can lead to a lack of informed decision making on the part of people with learning disabilities, resulting in harmful forced practices. This was discussed by Wiseman and Ferrie (2018)²² in a focus group with women with

²⁰ [Ali, et al \(2013\)](#)

²¹ [Joseph-Williams, Edwards, & Elwyn \(2013\)](#)

²² [Wiseman & Ferrie \(2018\)](#)

learning disabilities. One focus group respondent spoke about how a lack of information had removed their reproductive choices:

“When I went to the doctors to ask about contraception, I was not given the opportunity to explore the different options. I was told what one I should take... I wasn't encouraged to ask questions or supported to understand all my options....”

(Wiseman & Ferrie; 20018, p.17)

SCLD believes similar risks of overriding a person with learning disabilities choice and decision-making ability may be present in establishing informed consent for forensic examinations.

To address this, practitioners should be encouraged to practice protection with thoughtfulness. Ensuring that an individual's human rights and autonomy are preserved. This is clearly articulated by the Mental Welfare Commission (2016)²³ for Scotland advice notes on adults with incapacity and sexual relationships. This document states that Article 12 of the UN Convention on the Rights of Persons with Disabilities (2009),

“...Makes clear that persons with disabilities 'enjoy legal capacity on an equal basis within all aspects of life.', that states should provide the support disabled persons may require in exercising their legal capacity, and that measures relating to the exercise of legal capacity 'reflect the rights, will and preferences of the person.'”

(Mental Welfare Commission for Scotland; 2016, p.3)

²³ [Mental Welfare Commission for Scotland \(2016\)](#)

Informed consent for forensic examination must be based on accessible information and communication. This will involve active awareness of the potential of the aforementioned 'framing effect' and the potential to shield information from people with learning disabilities. The guidance should, therefore, address how communication can be tailored to ensure an understanding of a range of communication needs.

To mitigate these three central concerns highlighted in this response, SCLD would welcome the following recommendations being given consideration and being taken forward in and alongside the redraft of the guidance.

Guidance Recommendations:

- The guidance should address the experience of people with learning disabilities with regard to sexual assault and rape
- The guidance should reflect the importance of balancing rights and autonomy with protection. SCLD would welcome the opportunity to provide further advice on this and would recommend engagement with The Mental Welfare Commission
- Expand and develop the section on informed consent and capacity. This expanded section should address challenges in communication between professionals and people with learning disabilities. For example, the framing effect.
- Embed The Human Rights Act (1998)²⁴ and the UN Convention on the Rights of Persons with Disabilities (2009)²⁵ in the guidance.

²⁴ [The Human Rights Act \(1998\)](#)

²⁵ [The UN Convention on the Rights of Persons with Disabilities \(2009\)](#)

Further Recommendations:

- NHS Health Scotland to support the implementation of this guidance document with training on communication for frontline staff
- Examine the potential to commission further research regarding the experience of people with learning disabilities regarding medical and victim support following sexual assault and rape.

SCLD thanks The Scottish Government for the opportunity to respond to this important consultation and would welcome the opportunity to be involved in further discussions where appropriate.



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

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