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National Association for People with an Intellectual Disability

Disabled People for Choice

Disabled Women Ireland

AMNESTY INTERNATIONAL

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Submission to the Department of Health

On the Health (Regulation of Termination of Pregnancy) Bill 2018

October 2018

About this submission

This submission is a cross disability rights organisation submission on the Health (Regulation of Termination of Pregnancy) Bill 2018. Contributors include Inclusion Ireland, Centre for Disability Law and Policy, Lawyers for Choice, Disabled Women Ireland, Disabled People for Choice and Amnesty International Ireland.

As part of this submission there was a consultation held with persons with disabilities and their quotes are included in this submission.

An easy to read summary of this submission is also available.

Introduction

The United Nations Convention on the Rights of Persons with Disabilities asserts the right of individuals with disabilities to decide on the number and spacing of their children, to have access to reproductive and family planning information, education and healthcare[1], as well as the means to exercise these rights. The UN Human Rights Committee[2] recently affirmed that the State "must provide safe access to abortion to protect the life and health of pregnant women".

The result of the referendum in May 2018 to permit the Oireachtas to legislate for the regulation of termination of pregnancy is to be welcomed. This new legislation will replace the previous Protection of Life During Pregnancy Act (2013). The context of this Act was that abortion was illegal unless the pregnancy was life-threatening and lead to people with disabilities being disproportionally affected in a myriad of different ways by this law[3].

With the removal of this Article from the Constitution there is now an opportunity at this juncture to put in place legislation that will promote equality for persons with disabilities in accessing healthcare, and in particular in accessing abortion services. There is also an opportunity with this new legislation to move away from the previous amendment which placed accessing abortion services in a criminal light[4], to one which attempts to bring about abortion healthcare for people that are based upon the values of equality and human rights.

For persons with disabilities this legislation must not fall into the trap of previous laws such as The Lunacy Act, 1871 and The Criminal Law (Sexual Offences) Act, 1993. These Acts presume a lack of capacity of the individual, limit choice for people and restrict their rights. The current Bill provides huge scope to be pro-active in promoting people's reproductive rights, making supports available and giving individuals with disabilities the autonomy to make decisions.

This submission will examine the current Health (Regulation of Termination of Pregnancy) Bill 2018 and aims to highlight the various

[1] Articles 23 and 25
[2] Draft general comment No. 36 on article 6 of the International Covenant on Civil and Political Right, on the right to life
[3] Submission to the Department of Justice and Equality On a new National Women's Strategy 2017-2020
[4] Enwright, Fletcher, De Londras, Conway (2018). Position Paper on the updated General Scheme of the Health (Regulation of Termination of Pregnancy) Bill (2018).

issues and barriers that will affect persons with disabilities in the proposed legislation.

This will include looking at

1. The context for people with disabilities
2. Barriers to good healthcare
3. Accessibility and Decision-Making
4. 12 weeks and Delay
5. 3 Day Mandatory Waiting Period
6. Conscience-based refusal to provide care
7. Review Committee and Appeals
8. Information provision and Counselling
9. Interactions with current legislation
10. Recommendations
11. Conclusion

1. The context for people with disabilities

The social context for people with disabilities in Ireland must be considered in the development of this legislation. The current context for people with disabilities accessing healthcare services is a challenging one. People with disabilities face many barriers when trying to access healthcare. These include discriminatory attitudes, sexual and reproductive healthcare barriers, the cost of disability, institutionalisation, low expectations, and many other health inequalities. Provision for abortion must be made in a manner which guarantees access for disabled people, without additional barriers or hurdles.

Elements of this Bill have the potential to disproportionally affect people with disabilities compared to other social groups. In particular, those who are still residing in congregated settings throughout Ireland. According to the latest progress report on the implementation of Time To Move On From Congregated Settings there were still 2,579 people living in these institutions at the end of 2016[5].

[5] Progress Report On the Implementation of Time to Move On From Congregated Settings: A Strategy for Community Inclusion Annual Report 2016.

According to the latest Health Service Executive (HSE) figures in June 2018 there are also 1,313 people under the age of 65 who are inappropriately living in nursing homes. These people are receiving home care via the NHSS scheme in public and private settings. Further to this there are people with disabilities there are people living in the community who do not have access to community-based supports and accessible services.

All of these individuals are subject to significant rights and choice restrictions which will have an effect on the accessibility of healthcare services available to them. Evidence has already shown that there is a higher risk of abuse in institutional settings and a lack of choice and control for those residing in them. It is therefore imperative that this lack of choice and control isn't compounded by further barriers in this legislation. [6]

The current Bill must reflect a reality where people who are facing these barriers will have the appropriate supports available to them in order to access abortion services. People with disabilities need legislation that promotes access and supports and not legislation that that will further limit choice and control.

2. Barriers to good healthcare

Attitudes:

Many disabled people feel they have little choice over their healthcare providers and GPs with many relying on long term relationships with their GPs in order to overcome these barriers to health care. However, this isn't always possible. Medical practitioners are susceptible to the same attitudes and biases as the general population.

Attitudes are one of the main barriers to healthcare identified by people with disabilities. This is particularity prevalent in sexual and reproductive healthcare. A huge amount of stigma still exists around people with disabilities and sexuality, relationships and parenting. A paternalistic approach is prevalent in law, policy and practice. Disabled women are often neglected when it comes to contraceptive care and consultation, owing to assumptions about their lives.[7]

[6] Time to Move on from Congregated Settings A Strategy for Community Inclusion, 2011
[7] BPAS

However, the most recent NDA Attitudes Survey (2017)[8] showed that attitudes towards people with disabilities having sexual relationships have improved. Factors such as ratification of the Convention, media such as Sanctuary the film and the change in the criminal law have helped this change in attitude. The current legislation has the potential to continue this positive trend and must ensure non-discrimination.

When asked if adults with the following disabilities have the same right to fulfilment through sexual relationships as everyone else – the percentage who either strongly agreed or agreed is intellectual disability 78%, physical disability 88% and sensory disability 91%. Although these figures are relatively high and improving, it does demonstrate that a small negative attitude prevails, particularly about people with intellectual disability.

Physical Accessibility:

Most sexual health and family planning clinics in Ireland are not accessible to people with physical disabilities. Louise Bruton noted this earlier this year in her Irish Times column "I rounded up information on various sexual health services available in Dublin that have access facilities and services for disabled people. - Unsurprisingly, it's not a long list." [9]

Aside from the built environment in clinics and surgeries themselves, practices and procedures are also not accessible. A disabled woman may not be able to get on to an examination table, for example, and it is up to doctors to have other more accessible equipment so that all women can receive necessary healthcare. People with sensory disabilities may also have specific accessibility issues. For example, having access to sign language interpretation can be quite difficult as there are waiting times due to a lack of availability.

The multiple visits to a GP that will be required as a result of the 3-day window may be an additional barrier for people with physical disabilities or those with mobility issues. Having to make successive visits to a doctor in a short time-frame could be an exhausting experience for many people, especially for individuals who live in rural areas where transport networks are less accessible and journeys can be significantly longer and arduous.

Currently there are many obstacles facing people with disabilities accessing public transport. For example, this can be seen in the advance 24 hours notice required to give Irish Rail and Bus Eireann in order to

[8] Public Attitudes to Disability in Ireland Survey (2017)
[9] https://www.irishtimes.com/life-and-style/health-family/sexual-health-if-you-are-living-with-a-disability-is-not-a-level-playing-field-1.3406100

avail of wheelchair ramps. Typical barriers such as these could cause delays and further distress, in particular if there are multiple trips to doctors required.

Sexual Relationships & Reproductive Health

Disabled people face barriers in almost every aspect of health care, but these barriers are magnified in sexual and reproductive health care.

Ireland has only just ratified the United Nations Convention on the Rights of Persons with Disabilities and it is imperative that all legislation from this point is not just compliant with the Convention but also takes from the principles and language of the Convention. It should be noted that Article 25 of the Convention[10] is explicit about health care including sexual and reproductive health care:

> "Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes".

Until relatively recently people with disabilities have found accessing contraception difficult as medical practitioners were afraid that they would be facilitating criminality. Conversely, many women with disabilities have experienced forced contraception and sterilisation, something now prohibited unless it is 'therapeutic' or sanctioned by the High Court.

The repealing of the 1993 Criminal Law (Sexual Offences) Act has resulted in an improved but nonetheless still discriminatory piece of legislation. The 1993 Act had made an offence of sexual intercourse with a 'mentally impaired' person, unless they were married. The new Act has created a category of 'protected person' which will continue to have an impact on the freedom of a person with an intellectual disability to enjoy their rights to sexual relationships on an equal basis with others.

Persons with a disability experience inequalities which further impede their sexual health and reproductive rights. These include;

- Persons with disability do not get sufficient access to sexual education. Improved sex education was identified by the Joint

[10] Article 25

Oireachtas Committee on the Eighth Amendment of the Constitution as an essential component of reproductive rights[11].

- Persons with a disability face health inequalities in many aspects of their life, including accessing maternity services and access to contraception.

- Persons with disabilities do not have their rights to medical consent and bodily integrity respected in many cases, particularly in relation to medical treatment.

- Persons with disabilities have not enjoyed clear rights in relation to sexual relationships and as such their relationships may be secret or taboo.[12]

Further barriers that affect women's ability to access healthcare include:

- A lack of accessible information
- A need to be treated by a medical practitioner familiar with a woman's medical history
- Difficulty in travelling due to lack of accessible transport and support services
- Poverty and lack of money

Research has shown that one of the most difficult barriers to women is with their health care providers. Providers were described as insensitive and reserved about family planning or sexually transmitted diseases and being treated as asexual beings[13]. Research into the extent of screening for breast cancer for post-menopausal women with learning disabilities living in residential care revealed that of the sample who received invitations to attend mammography breast screening, 93.5% attended. However for a number of reasons 16% were unable to complete the

[11] https://www.oireachtas.ie/en/debates/debate/joint_committee_on_education_and_skills/2018-05-15/3/

[12] Section 5 of the Criminal law (Sexual offences) Act 1993 created a'chilling effect' on persons with disability getting information and support. The Criminal Law (Sexual Offences) Act 2017 still discriminated against persons with disabilities.

[13] Becker et al., 1997

procedure, 26.7% received only a manual breast examination and 24% of the entire sample did not receive any breast screening at all.[14]

A lack of access has knock on effects for all healthcare, disabled people are underrepresented in smear test statistics in the UK for example. Studies on maternal mortality in the UK and Ireland show that between 2013-2015 68% of maternal deaths in Ireland were women with disabilities – ranging from uncontrolled asthma to psychosocial disabilities.

It is also important to consider the barriers to care that exist outside the health care system. Roughly 6000 young people are living in congregated settings or in nursing homes. Many people live in service provider housing, or are reliant on personal assistance. There are roughly 3000 people currently in the ward of court system in Ireland. Their right to make decisions are entirely eroded. Disabled people outside of the wardship system also face challenges to their decision making. The guarantee of autonomy that is being extended to people as a result of this referendum must be extended to disabled people.

Women and girls with disabilities experience intersecting forms of discrimination because of their gender. This is recognised by Article 6[15] of the Convention on the Rights of Persons with Disabilities. This may be further compounded by discrimination on the basis of 'race', ethnicity, age, migration status, geographic location, sexual orientation and gender identity among other factors. As with any piece of legislation, ensuring equitable access must take into account the reality of how people experience various and intersecting forms of discrimination in their daily lives.

Cost of Disability

For persons with a disability who can become pregnant the extra costs associated with multiple visits to a local GP over the 3 day mandatory waiting period would be significant barrier to accessing abortion services. These costs include GP costs, childcare costs, travel costs and time taken off work. Persons with disabilities are more likely to live in poverty compared to people in the general population. One in four persons with disabilities live in consistent poverty compared to one in twelve of the general population. As already mentioned, persons with disabilities

[14] Lalor, A. & Redmond, R. (2009). Breast screening for post-menopausal women. Learning Disability Practice. 12, 9, 28-33
[15] Article 6

already experience a myriad of health inequalities, and poverty disproportionally affects persons with a disability as a social group.

Evidence from the Survey on Income and Living Conditions (SILC) indicates that persons with a disability have the lowest levels of real disposable income. There is significant evidence that the additional, essential and recurring costs of having a disability can place a household at risk of poverty and deprivation. A report by Cullinan et al found that the estimated cost of disability is equal to 35 to 55% of average weekly income[16]. Therefore, people with a disability, in reality, experience greater levels of poverty as the cost of their disability has not been accounted for.

More research is being done into the barriers that exist for disabled people in sexual health, pregnancy care, abortion care and parenting. It is imperative that this legislation does not create more barriers, in what is already an unlevel playing field.

3. Accessibility and Decision-Making

The current Bill contains no provision guaranteeing safe and timely access to abortion. Neither does it provide for remedies where abortion care is delayed or wrongfully denied. The proposed legislation should provide for a guarantee of access to care, including ensuring that access is not impeded on discriminatory grounds.[17]

The current Bill makes no reference to any advocacy supports for people with disabilities in accessing abortion services. Advocacy supports must be made available to those who wish to use them. These supports must be free, professional and available in a timely manner so it does not delay or impede the access to abortion services. Advocacy is crucial for enabling persons with disabilities to enjoy their rights and entitlements. Persons with disabilities may require a broad range of advocacy services and supports and this should be no different for persons who may need support to access abortion services.

[16] Cullinan, J., Gannon, B. and Lyons, S. (2010). Estimating The Extra Cost of Living for People with Disabilities. Health Economics

[17] A Model for Change (Enright, Mairead et al (2015) feminists@law, Vol 5, No 1 (2015)) and Fiona de Londras and Mairead Enright *Repealing the 8th: Reforming Irish abortion law* (Policy Press, 2018).

There has been an increasing use of the ward of court system as provided for by the Lunacy Act, 1871 where there is doubt as to the decision-making capacity of an individual. Traditionally, the provisions of the Lunacy Act were only used where there was a significant estate involved, but increasingly the jurisdiction is being used for welfare and health decisions. There is a serious risk that persons with a disability may be made a ward of court, exclusively to facilitate access to abortion care. It is essential that accessible information and advocacy is considered in order to minimise the potential for people being made a ward of court.

The features of the Assisted Decision-Making (Capacity) Act ensure that people are supported to make decisions in the most suitable way appropriate for them. The supports envisaged by the Act must not be used to delay or impede access to abortion services. It is important that people are presumed to have capacity to make their own decisions, and that being made a ward of court is not the default route for decisions related to abortion care.

Further, it is vital for clarification to be provided regarding the standard of consent in the Termination of Pregnancy Bill and its application to persons who may be subject to the provisions of the Assisted Decision-Making Capacity Act. If the 2018 Bill proposes to use the functional assessment of mental capacity to determine whether free and informed consent to a termination of pregnancy has been provided, this must not be applied in a manner which discriminates against persons with disabilities. In the event that a person requesting a termination of pregnancy is considered by her doctor to lack capacity to make this decision, it is critical that an application is heard urgently under the 2015 Act, particularly where the request is made within the 12 week timeframe, as any delays could result in the denial of access to abortion care. Practitioners need clear guidance on when and how to make applications under the 2015 Act for decisions relating to the 2018 Bill.

In addition to this it is important that information relating to abortion services is made accessible in a variety of formats. This includes having information in easy-to-read, plain English so that information is clear and easy to understand for persons with disabilities.

What people said in our consultation about Accessibility and Decision-Making

"It is my body so I can only make that decision; it is not up to the doctor".

"Support workers need to support people properly when making these decisions".

"People will need support before, during and after making a decision".

"Yes it is important that information is accessible and easy to understand".

"In order to truly make the Termination of Pregnancy Bill inclusive and accessible for all, our Government needs to enact the Assisted Decision Making Bill and repeal the Lunacy Act fully."

4. 12 weeks and Delay

Under Section 13, abortion is accessible up to 12 weeks Last Menstrual Period (LMP).

> Last Menstrual Period (LMP) means the time counted of a pregnancy from the first day of a person's last period.

Consideration should be given to extending the time period within which abortion can be accessed in early pregnancy; to at least 14 weeks LMP. Failing that, clear measures must be taken to avoid delays in accessing treatment, particularly where a person seeks treatment close to the 12 week deadline.

People with disabilities in Ireland have poor access to sex education, which may mean that they may fail to recognise an early pregnancy.[18] Once the pregnancy is discovered, pregnant people need adequate time to reflect on and understand their options, and to make a decision. The challenges of unexpected pregnancy may be compounded for people with

[18] Burgen, 2010. Women with Cognitive Impairment and Unplanned or Unwanted Pregnancy: A 2-Year Audit of Women Contacting the Pregnancy Advisory Service

intellectual disabilities, who are often not supported to continue pregnancy and parent children.

Similarly for pregnant people with any type of disability as people may require extra time to research and consider their options. For example, for a parent with a disability, there should be additional supports made available for the person and the child if needed. There is a general lack of transparency and information on how to access supports and services. The Child Care Law Reporting Project 2015[19] pointed to the fact that parental disability emerges as a major factor in one in six child-care cases. That report recommended that assessments were provided and supports put in place. This needs to be addressed to enable people to make informed decisions about a pregnancy.

Some may struggle to make initial contact with a doctor, particularly where they need to travel to access healthcare, or need another person's assistance to do so. Others may find themselves in complex situations as, for example, where their situation is governed by both the law on capacity and the law and abortion, or the law on abortion and mandatory reporting policies related to 'vulnerable adults'. Complex circumstances may make timely access to abortion care much more difficult. The overlap of these processes, their interplay and differing timeframes could have a significant negative impact on a person and cause them more distress while trying to access abortion services.

Further possibilities for delay arise at each stage of the process:

- Travelling and attending the first GP appointment so that they can be examined and the pregnancy can be dated and the entitlement to access an abortion can be certified.
    - If the pregnancy is suspected to be over 9 weeks, it now seems likely that the GP will refer the patient for scanning at a hospital. This generates further scope for delay; travelling to the hospital for the first appointment and ultrasound scan.[20]
    - If the pregnancy is over 9 weeks they may be certified at the hospital. If it is under 9 weeks, they may be referred back to her GP for certification. Section 13 requires that the doctor who examines and certifies the person must also perform the abortion.
- If the GP holds a conscientious objection, finding a new GP.

[19] Child Care Law Reporting Project (2015)
[20] START Doctors position paper http://startireland.ie/resources/start%20position%20paper.pdf;

- The 3-day mandatory waiting period.
- Travelling to and attending the second GP appointment, at which (presumably) the abortion pill is prescribed and mifepristone administered.
- Resolving any difficulties around capacity to consent to treatment.
- The termination itself. A person may be prescribed misoprostol to take at home 24-48 hours after the original appointment, or they may be required to return to the GP/hospital for a further appointment. [21]
- There may be a third appointment for aftercare, perhaps counselling and sex education.

These sites of potential delay apply to every patient under the proposed system. However, some people with disabilities face particular difficulties for the reasons already mentioned. A person with a disability who 'misses the deadline' may be required to travel abroad for a termination or may be forced to access abortion illegally. Missing the deadline could also result in a person having to go through with the pregnancy despite this being against their wishes.

One option would be a new provision inserted into legislation allowing for 12 week wait to be waived in some cases, where the pregnant person would otherwise not be able to access care within the 12 week deadline; however, such a 'hardship' clause could pose difficulties in interpreting the legislation and ensuring that it is consistently applied.

Implementation guidelines should ensure that information is available in easy to read formats, and that appointments are long enough to allow for discussion of the pregnant person's concerns.

[21] START Doctors position paper
http://startireland.ie/resources/start%20position%20paper.pdf

What people said in our consultation about 12 weeks and Delay

"If the doctor feels that the person can make that decision then there shouldn't be a delay".

"People will need support before, during and after making a decision".

"Not everyone experiences the other obvious signs of pregnancy such as morning sickness".

"Should people with a disability/chronic illness find themselves pregnant, it can often be quite late into a pregnancy. We are worried for people in this situation if they do not discover that that they are pregnant until just before or after the 12-week period. "

5. 3 day Mandatory Waiting Period

The mandatory waiting period in Section 13(3) should be removed. There is no medical or legal basis for having a 3 day waiting period in the legislation. Any waiting period will provide a barrier for people with disabilities and in particular for people with intellectual disabilities who struggle to make travel arrangements, or whose everyday autonomy is restricted. It is likely to lead to delay in accessing care and affect those who may be unable to make multiple doctors' appointments.

Any waiting period that is included should be the least restrictive possible and implementation guidelines should clarify that the 'clock' starts running from the first moment of contact with the health service[22] (e.g. the GP and telephone helpline). Having a one size fits all approach in place for people who have different opinions, needs and decision-making capacity is not good practice and removes people's ability to make decisions with the supports that are most appropriate for them.

Persons with disabilities who were consulted on this submission expressed concern at the proposed 3 day waiting period. A 3 day waiting period could be offered to people to avail of if needed and should not be a

[22] START Doctors position paper http://startireland.ie/resources/start%20position%20paper.pdf

blanket requirement for all who want to access abortion services. A 3 day waiting period which is optional would be much more in line with the Assisted Decision-Making (Capacity) Act so as to give each individual the supports needed to make a decision. There is a possibility that the imposition of a 3 day waiting period could have detrimental effects on people who have already come to making the difficult decision to terminate a pregnancy. There is no guarantee that having a 3 day window in place serves as a period of reflection as suggested. Instead, this window could add to a person's stress and anxiety levels, making the situation much worse. This period could also open up the person to coercion in their decision-making process.

Further to this, many people with disabilities struggle to attend a GP so forcing individuals to attend a GP on two or more occasions could lead to increased emotional stress, anxiety and physical strain for those involved, where they would be required to visit a GP on more than one occasion. There is also the added dimension of increased financial stress that would result from multiple GP visits in the form of GP costs, transport costs and other possible costs.

As mentioned in the previous section there should be a process in place where some individuals do not have to be subject to a waiting period but are instead supported to make decisions based upon their individual needs.

What people said in our consultation about the 3 Day Mandatory Waiting Period

"What is the point of the 3 day window if you're up against time?"

"Going to the doctor twice could raise your anxiety"

"A 3-day window would put a lot of pressure on me"

"Having to pay for a doctor on 2 occasions would be a barrier for me, I couldn't afford it."

"Many people with disabilities have mobility issues and experience flare-ups of their illness. This means the simple act of getting out of the house can be an enormous task, especially in rural areas. To ask people with disabilities to organise travel twice in one week could prove to be an impossible task."

6. Conscience-based refusal to provide care

This section refers to the current Bill's inclusion of conscientious objection in Head 23 of the new legislation. The inclusion of this Head amounts to a refusal to provide a safe and legal service to individuals. The General Scheme provides for conscientious objection on the same terms as the Protection of Life During Pregnancy Act, 2013. Medical professionals may refuse to certify a person's entitlement to access an abortion, or may refuse to provide abortion care on the basis of a conscientious objection under Section 23. Only those participating in carrying out the termination of pregnancy are entitled to withhold care, and a provider may not refuse to provide abortion aftercare.

Under Head 23(3), those asserting a conscientious objection must make timely arrangements for transfer of the pregnant person's care, to ensure that they can access a termination of pregnancy. This is important as while the provision to conscientiously object is based on a constitutional right to freedom of religion and conscience under Article 44.2.1, this right is 'subject to public order and morality'. An absolute right to 'opt out' of providing abortion care would undermine the countervailing rights to bodily integrity, privacy and freedom from inhuman and degrading treatment.[23] For reasons already discussed, relating to accessibility and poverty, non-referral of a person with a disability to a nearby doctor could provide an insurmountable barrier to accessing healthcare.

We advise that the Section 23(3) referral provision should be retained in the final legislation. As already discussed, people with intellectual disabilities can face obstacles both in accessing healthcare, and in obtaining accessible healthcare information. People living with a family member who objects to abortion or in a congregated setting where a religious ethos applies, may face particular challenges in accessing a supportive local doctor. It is important, therefore, that any doctor they approach has a responsibility to assist, as envisaged by the referral obligation. If provision is made for conscientious objection, the legislature

[23] See *LMR v. Argentina* UN Doc. CCPR/C/101/D/1608/2007), noting that violations of human rights resulting in mental suffering may be exacerbated where the victim has an intellectual disability.

must ensure that it does not particularly impact on people with disabilities [24]

If pregnant people bear the burden of accommodating conscientious objection, they may be required to begin the search for an abortion provider from scratch upon refusal of care. This may lead to delays in accessing treatment, or ultimately to inability to access it at all. An information service, such as a phone-line or a website, cannot always discharge the state's obligations to the pregnant person in this context; the pregnant person may struggle to process available information, make new arrangements and keep appointments.

Any doctor who is in receipt of public funds through medical card treatment should have an increased duty of care of to provide abortion services and at a minimum must refer the person to the most proximate doctor. Individuals, including those with disabilities, who use a medical card do not always have the same access to doctors and may find a change of doctor to be administratively difficult or time-consuming in what is already a time-sensitive situation. It is important that any referral does not cause the person any undue stress and there is not an onus on the person to source another doctor. In-person referral by one's own chosen, or familiar[25] community healthcare provider, may be the most appropriate means of ensuring equal access to abortion care for persons with intellectual disabilities.

Consideration should be given in Implementation Guidelines to ensuring that the doctor's conscientious objection, and its consequences for the pregnant person, is clearly communicated to the person in accessible language. Furthermore, it is imperative that the legislation makes clear that conscientious objection does not apply to health institutions. Particularly for people with disabilities who are living in geographically isolated areas, if an institution as a whole objects to providing access to services, this could make the burden of travelling to alternate providers insurmountable.

If health professionals are permitted to refuse to provide abortion care services, it is important that comprehensive and disaggregated data is

[24] We note IHREC's recommendation that "provisions governing conscientious objection, and related obligations to refer a pregnant woman to an alternative care provider, should cover a broader range of health and social care professionals than is currently allowed for." If provision for conscientious objection were to be extended to broader health and social care professionals, then particular consideration must be given to how this would operate and potentially impact people with disabilities. Human Rights and Equality Commission Calls for Conscientious Objection and Access Provisions to be Clearly Set Out in Abortion Legislation.

[25] Centre for Disability Law and Policy (2016). Submission to the Citizens' Assembly on Repeal of the Eight Amendment to the Constitution. Galway: CDLP.

collected on refusals. As with the Gender Recognition Act a review clause could be inserted into the legislation. This would allow for the legislation to be reviewed and strengthened after two years, based upon any data and other evidence showing where there are gaps in the implementation. [26]

If disaggregated data were collected then the rates of refusal for people with disabilities could be collected and any refusals related to health institutions would be transparent. [27] This is particularly important for people who live in institutions and congregated settings and for those settings where a religious ethos applies.

What people said in our consultation about Conscientious Objection

"People with disabilities generally have the same GP their whole lives or at least for a large portion. They know your medical history; everything from the physical to the mental wellbeing of their patients."

"No a doctor shouldn't be able to refuse to help you have an abortion".

"They have a duty of care regardless of their views".

"Their job is to help people".

"I would rather keep going to the doctor I know".

"That would knock my confidence if I have to go to another doctor, I don't know if I could trust them again to go back".

7. Review Committee and Appeals

Under Section 14, a pregnant person who is refused access to an abortion after 12 weeks, or whose doctor does not give an opinion on whether she is entitled to access an abortion, is entitled to apply to the HSE for a review of that decision. The pregnant person must be informed of that

[26] Amnesty International (2018). Submission to Department of Health on the Updated General Scheme of a Bill to Regulate Termination of Pregnancy
[27] *Ibid*

entitlement in writing. Another person may apply for a review on her behalf. Under Section 18, the pregnant person or her representative is entitled to be heard by the review panel, which shall consist only of medical practitioners. The panel may make necessary arrangements to ensure an effective hearing. There is no appeal from a decision of this committee except, presumably, by means of judicial review.

These provisions mirror the review provisions of the Protection of Life During Pregnancy Act, 2013. The Department of Health does not publish data on the operation of that review process (aside from enumerating appeals) and so it is difficult to evaluate it. However, many of the criticisms of the 2013 process remain relevant here:[28]

- Guidelines should clarify whether the pregnant person will be subjected to further, potentially distressing examination.

- The legislation should provide, in clear terms, for a right to assistance and supports in accessing and participating in the review.

The review procedure does not apply where the person is refused an abortion at 12 weeks or below. It is important that any person refused access to an abortion receives clear reasons for the refusal, and accessible information on how they can access a termination to which they may be legally entitled.

[28] IHREC, *Observations on the Protection of Life During Pregnancy Bill* July 2013 https://www.ihrec.ie/download/pdf/ihrc_observations_protection_of_life_in_pregnancy_bill_2013.pdf

What people said in our consultation about the Review Committee and Appeals

"We are concerned about this process and the time it will take to make this decision".

"The longer a decision takes, the longer the person remains pregnant. With disability/chronic illness, an abortion can be more complicated so it is imperative that termination is carried out as early as possible to avoid risk to the person's mental and physical health".

"Later terminations also have their own added risks for people with disabilities so a time limit on this review process must be considered. We feel it is also important that an expert in the field of the patient's disability is part of this review process to highlight the potential risks of continuing with a pregnancy".

8. Information provision and Counselling

It is important that the implementation guidelines make the distinction between providing people information about abortion services and people receiving support in the form of counselling – where that counselling is requested by the person. There should be a requirement that the HSE make counselling services available for people who wish to avail of it - if that counselling be required for crisis pregnancy or in the case of post-abortion counselling. There should not be an onus on people themselves to search and find counselling services in their area.

In our consultation with persons with disabilities individuals highlighted the need for an independent information and support service that can provide the appropriate supports for people to make decisions and be aware of the services that are available to them. This information service could take the form of an accessible website, a phone line. This service should also have information about every step of the process for making a decision, from making a decision, attending the GP and what supports are available thereafter.

There is also an opportunity at his point for the legislation to establish an independent advocacy service that people with disabilities can access. This could also be a role for the recently established Decision Support Service (DSS), as well as the National Advocacy Service (NAS).

What people said in our consultation about Information Provision and Counselling

"There should be accessible information at every step of the process of making the decision. From when you're making the decision to when you attend the GP, to support you might need after".

"There should be a website with information on abortion that is accessible for people.

"There should be an online chat and a phone line you call up to ask questions."

"This could be counselling, a chat group or a workshop"

"There should be independent advocacy available for people to make their decisions"

"it is important that people are supported properly before the 12 weeks are up"

9. Interactions with current legislation

The proposal of the current Bill raises specific concerns around existing Acts and how these Acts will interact with the Health (Regulation of Termination of Pregnancy) Bill 2018. These concerns centre on the lack of clarity around which legislation will take precedence in complex situations, and the pathways for access for pregnant people with disabilities.

Assisted Decision Making (Capacity) Act 2015

As noted above, there is a need for clarity on how consent to a termination is to be determined and what steps should be taken if there are concerns that the person requesting the termination does not have the capacity to make this decision in section 3.

Section 85 of the Assisted Decision-Making (Capacity) Act is concerned with the validity and applicability of advance healthcare directives. This section makes provision for the difference in treatment of a directive depending on where a directive maker is pregnant.

Where a directive-maker lacks capacity and is pregnant and their advance healthcare directive does not specifically state whether a refusal of treatment should apply if the person were pregnant, it is presumed that the treatment will be continued if its refusal would have a deleterious effect on the unborn.

Section 85(6)(a) says that if a directive-maker lacks capacity and is pregnant and their advance healthcare directive does sets out a specific refusal of treatment that is to apply even if they were pregnant, and it is considered by the healthcare professional concerned that the refusal of treatment would have a deleterious effect on the unborn, then an application to the High Court should be made to determine whether or not the refusal of treatment should apply.

The High Court is required to consider several things with the potential impact of the refusal of treatment on the unborn the first on the list and the invasiveness and the risk of harm to the directive-maker second.

This provision appears to have been put in as a direct result of Article 40.3.3 on the Constitution and its continuation is no longer legally required. We recommend that 85(6)(a) of the Act be deleted in its entirety as it is no longer required as to the validity of an advance healthcare directive.

Criminal Law (Sexual Offences) Act 2017

The Act makes it an offence to engage in a sexual act with a protected person. A protected person is someone who lacks capacity to engage in a sexual act by reason of a mental or intellectual disability or a mental illness. There is another offence of sexual acts with a "relevant person" by a "person in authority". A relevant person is described as relevant person" a person who has a mental or intellectual disability or a mental illness which is of such a nature or degree as to severely restrict the ability of the person to guard himself or herself against serious exploitation.

Because of the broad nature of this legislation, it is entirely possible that a person with a disability could become pregnant through the commission of a criminal act or abuse. It is essential that a person who is considered a protected or relevant person is not presumed capable of making decisions in relation to the continuation or termination of the pregnancy and the guiding principles of the Assisted Decision-Making (Capacity) Act should apply.

Citizens Information Act, 2007

Because the Citizens Information Act, 2007 hasn't been commenced fully advocates do not have statutory powers to act. This is particularly concerning in adversarial situations and will impact on how advocacy providers such as the National Advocacy Service (NAS) provide its service to people with disabilities.

10. Recommendations

Outlined below are the recommendations from this submission

1. People with disabilities need legislation that promotes access and supports and not legislation that that will further limit choice and control.

2. The Assisted Decision-Making (Capacity) Act must be amended to take into account this new legislation. We recommend that 85(6)(a) of the Act be deleted in its entirety as it is no longer required as to the validity of an advance healthcare directive.

3. Advocacy supports must be made available to those who wish to use them.

4. The proposed legislation should provide for a guarantee of access to care, including ensuring that access is not impeded on discriminatory grounds.

5. Information relating to abortion services is made accessible in a variety of formats. This includes having information in easy-to-read, plain English so that information is clear and easy to understand for persons with disabilities.

6. Consideration should be given to extending the time period within which abortion can be accessed in early pregnancy; to at least 14 weeks LMP. Failing that, clear measures must be taken to avoid delays in accessing treatment, particularly where a person seeks treatment close to the 12 week deadline.

7. A provision could be inserted into legislation allowing for 12 week wait to be waived in some cases, where the pregnant person would otherwise not be able to access care within the 12 week deadline.

8. The mandatory waiting period in Section 13(3) should be removed. There is no medical or legal basis for having a 3 day waiting period in the legislation.

9. Any waiting period that is included should be the least restrictive possible.

10. Any doctor who refuses to provide abortion care has a responsibility to assist. Pregnant people must not bear the burden of accommodating conscientious objection and should not be required to begin the search for an abortion provider from scratch upon refusal of care. This is particularly true for medical card holders.

11. Conscientious objection must not apply to health and residential institutions as this could have hugely detrimental effect on persons with disabilities living in both the community and in congregated settings.

12. If health professionals are permitted to refuse to provide abortion services, comprehensive and disaggregated data must be collected on refusals.

13. As with the Gender Recognition Act a review clause could be inserted into the legislation. This would allow for the legislation to be reviewed and strengthened after two years, based upon any data and other evidence showing where there are gaps in the implementation.

14. The legislation should provide, in clear terms, for a right to assistance and supports in accessing and participating in the review committee.

15. It is important that any person refused access to an abortion receives clear reasons for the refusal, and accessible information on how they can access a termination to which they may be legally entitled.

16. There should be a requirement that the Health Service Executive (HSE) make counselling services available for people who wish to avail of it - if that counselling be required for crisis pregnancy or in the case of post-abortion counselling.

17. An independent information and support service should be established that can provide the appropriate supports for people to make decisions and be aware of the services that are available to them.

11. Conclusion

In the current context of healthcare access in Ireland today, people with disabilities face great inequality. These inequalities take many forms and include barriers related to physical accessibility, information accessibility, poor attitudes toward disability, discrimination in access reproductive health and the disproportionate effect of poverty and the cost of disability for disabled people. All of these factors could combine to make accessing abortion services much more challenging for people with disabilities.

Many aspects of the Bill such as the 12 week limit and the 3 day mandatory waiting period will disproportionately affect people with disabilities. Complex situations could lead to delays for people with disabilities in identifying their pregnancy and in then accessing abortion care thereafter. Other aspects, such as the inclusion of conscientious objection whereby medical professionals will have the option to refuse to provide abortion healthcare to individuals is deeply concerning for people with disabilities. This will have a hugely detrimental effect and it is important that people with disabilities do not bear the burden of having to find another medical professional and that any GP who does refuse to provide healthcare makes appropriate arrangements for an alternative GP.

People with disabilities must be supported through making a decision on a pregnancy. This involves once the pregnancy being discovered, pregnant people being given adequate time to reflect on and understand their options in order to make a decision. This requires appropriate supports in the forms of advocacy, accessible information and counselling being made available to those who need it.

This new piece of legislation is an opportunity to promote the rights of people with disabilities and not fall into the traps of previous laws that limit the choice and autonomy of individuals. It is important the legislation takes from the principles of the Convention and instead of perpetuating barriers for people; the legislation instead promotes autonomy, choice, and decision-making for all persons with a disability.

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