

**Statement on Reproductive Justice and Disabled Women to the Oireachtas Joint Committee on Disability Matters**  
**Selina Bonnie MA – Tuesday, 9 March 2021**

Thank you for the opportunity today to share my experiences and observations regarding reproductive justice, particularly for disabled women in 21<sup>st</sup> century Ireland. I am here not only as a member of the NWC Disabled Women's Group and Vice Chair of Independent Living Movement Ireland which is a disabled person's organisation (DPO), but also as a survivor of Irish assisted human reproductive services and a regional ambassador for the NUIG Centre for Disability Law and Policy Re(al) Productive Justice initiative. I would like to acknowledge the research team in Galway for their support with my statement.

I speak to you as a disabled woman and not a woman with a disability. This fundamental social rights-based definition underpins my statement and indeed my life.

According to Census 2016 the total number of disabled persons in Ireland is 643,131 (13.5% of population). Almost half are disabled women. However little attention has been paid to the specific experiences and needs of disabled women in Ireland. For example, 63.7% of disabled women are mothers and yet disabled women are not mentioned in our current maternity strategy.

This morning I plan to focus on two key issues of reproductive justice. These are assisted human reproduction, and disabled women's access to essential health services.

So what is Reproductive Justice?

Reproductive justice is the ability to make decisions, and have choices respected, around becoming a parent or not. This includes fertility, contraception – including assisted human reproduction, abortion, pregnancy, birth and parenting – including fostering and adoption. The Re(al) Productive Justice project has identified discrimination for disabled people on these issues in many forms. These include:

- Physical infrastructure where reproductive health and parenting services are delivered being inaccessible.
- Historic and contemporary use of long-term contraceptives without informed consent.

- Ableist attitudes across assisted human reproduction, maternity and parenting service staff.
- A lack of accessible information across all stages of reproductive decision making,
- Gap in knowledge from health professionals about the support needs of disabled people accessing reproductive services.
- Increased interventions and monitoring of disabled parents which is disproportionate to non-disabled parents.
- Lack of uniformity about the use and quality of Parental Capacity Assessments.
- There is a gap in data about the provision of reproductive services to disabled people, particularly with the new framework for abortion services.
- The current legal capacity framework and delay in full realisation of the UNCPRD contributes to violations in this part of disabled persons lives.

Disabled people, with genetic / hereditary impairments, particularly disabled women, (as the female body is the primary site of most Assisted Human Reproduction treatments), often meet significant resistance from the medical profession, when attempting to access assisted fertility services. I have experienced this discrimination and based on my personal experience, and as an activist and academic in the area of reproductive justice for disabled people, I have significant concerns about the General Scheme of the Assisted Human Reproduction Bill 2017 and its' potential negative impact on the rights of disabled people to access assisted human reproduction services.

My main areas of concerns are Head 7 - Welfare of the Child and Head 30 - Pre-Implantation Genetic Diagnosis (PGD). For the purposes of brevity today rather than orally detailing my concerns I have included them as an appendix to my written statement.

However, my urgent concern that that there is a glaring absence of voices / experiences of people identifying as disabled in the public meeting list of witnesses and 31 written submissions of the Pre-legislative Scrutiny of the General Scheme of the Assisted Human Reproduction Bill 2017. This must be rectified before the Bill progresses any further.

Due to accessibility issues and lack of universal design in mainstream services, disabled women often experience poorer access to health and social care services. Disabled

women experience barriers to accessing health screening services resulting in lower uptake of breast and cervical cancer screening.

Qualitative and quantitative data is not collected based on disability. It is essential that this be addressed to enable future planning of services so that they are more accessible and inclusive. Qualitative data is particularly essential as often the lived experience can radically demonstrate where services that appear inclusive and accessible on paper are failing. For example, I have heard countless accounts from fellow disabled women of how the services are failing them.

Depending on the equipment available in individual GP surgeries, and the location of colposcopy clinics, many disabled women are faced with significant travel to access services that meet their individual support needs. Often the ability of disabled women to access these essential services will depend on accessible transport, allocation of sufficient personal assistance hours or appropriate ISL interpretation.

In addition to physical and information access issues, attitudes also have significant impact. For example, the CervicalCheck Women's Charter informs disabled service users: "If you have special needs and require assistance in accessing the programme, CervicalCheck will support you". Disabled women do not have 'special' needs we have specific access needs.

With regard to disabled women who are wheelchair users BreastCheck state that some wheelchairs can be used by women using the mammogram machine, depending on the size, weight and adaptability of the arms of the chair. For women whose wheelchairs are not appropriate, a screening chair can be provided to enable access. They do not however mention if a hoist will be available and I have heard many stories of where disabled wheelchair users have not been provided with hoist access and they have been made to feel as if they are in the wrong for needing the access.

In general, there is a significant need for innovation and universal design in the medical field. Disabled women are not the problem – the responsibility lies with the designers of services and equipment. We can put a rover on Mars, but we cannot design universally accessible diagnostic or therapeutic equipment!!

In conclusion, we need gender sensitive and accessible health services that are delivered with dignity and sensitive to the diversity of disabled women's needs, experiences and backgrounds.

Every individual has the power to effect change. You as elected representatives have a greater power and therefore a greater responsibility to use your power, individually and collectively, to effect change. I will conclude my statement this morning with my recommendations for how you can effect positive change for disabled women with regard to reproductive rights.

- Ensure data collection disaggregated by disability in essential areas such as BreastCheck, CervicalCheck, and all reproductive health services.
- Strongly advocate for innovation of accessible, inclusive services and universal design.
- Meaningfully address the absence of disabled people's voices / experiences from pre-legislative scrutiny of Assisted Human Reproduction Bill 2017.
- Ensure the Ethics Committee of the AHR Regulatory Authority, when established, includes the voice of disabled people.
- Consider disabled people's access needs in all areas of service provision and not just the public areas of life such as transport, education and so on. Access to the realisation of private rights such as reproductive justice are essential for quality of life.

Disabled women need, and have a right to expect, accessible health and reproductive services that are delivered with dignity and that are sensitive to the diversity of our needs, experiences and backgrounds including race, sexuality, gender identity and disability.

Thank you and happy International Women's Day!

## **Appendix One**

### **Concerns regarding the General Scheme of the Assisted Human Reproduction Bill 2017 and the pre-legislative scrutiny (July 2019) of the Bill**

Head 7 - Welfare of the Child. The Bill states that “due regard shall be given to the health and wellbeing of children born as a result of such treatments”.

In its section exploring the potential implications of the Equal Status Acts 2000 - 2015 for Assisted Human Reproduction (AHR), the 2005 Report of the Commission on Assisted Human Reproduction (CAHR), states that Sub-section 4 (of the Acts),

‘provides that where a person has a disability that could cause harm to that person or to others, treating the person differently to the extent necessary to prevent such harm shall not constitute discrimination.’ (CAHR, 2005: 136).

I understand this to imply that currently if a disabled person were to legally challenge a fertility specialist over refusal of treatment, the disabled person would not be protected by the Equal Status legislation purely because they could not guarantee that they would not have a disabled child.

I had hoped that the AHR Bill 2017 would appropriately deal with this issue, but based on the report of the pre-legislative scrutiny I do not believe that it has. However I note that the report of the Pre-Legislative Scrutiny of the Bill recommends that further clarity must be provided in respect to the provision dealing with the welfare of the child. It is essential that disabled people participate in work to clarify this issue.

Head 30 provides that Pre-Implantation Genetic Diagnosis (PGD) would be permitted only in cases where there is a significant risk of a child being born with a serious genetic disease that is included on a list to be established and maintained by the regulatory authority and that the potential impact on health, well-being and quality of life of the person to be born should be taken into account. It is essential that disabled people participate in the clarification of PGD. Measuring well-being and quality of life can be very subjective based on the life experience of the person carrying out the ‘measuring’, and therefore the potential for eugenic policy and practice is extremely concerning.



**Selina Bonnie MA - March 2021**

Selina is an Indian / Irish disabled woman who holds a Master's Degree in Disability Studies from the University of Leeds and a Professional Diploma in Human Rights and Equality from the IPA / IHREC. She has been an activist, lecturer and trainer in the international disabled people's movement for more than 25 years. Her particular research interests centre on sexuality, sexual expression and reproductive rights for disabled people. Selina has been published on related topics in various fora including a chapter titled 'Towards Sexual Citizenship: Dispelling the Myth of Disabled People's Asexuality', in the book *Sexualities and Irish Society: A Reader*. She is currently the Vice Chair of Independent Living Movement Ireland (ILMI) and a Regional Ambassador for the NUIG Centre for Disability Law and Policy Re(al) Productive Justice Research project. She is also a busy wife, mother and passionate home chef who works full time for South Dublin County Council as their Disability Liaison, Access and Equality Officer.

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