

Disabled from autonomy:

**exploring the space
between disability and
women's rights in an ablest
world.**

Alyce NELLIGAN.





Welcome

Alyce Nelligan is a community advocate, political activist, artist, and proud disabled woman.

Alyce has been a four time- candidate for the Greens, is a disability advocate, involved in many national organisations including being a member of the Y Connect Advisory Board for YWCA Australia, is a brand ambassador for an Australian fashion label, Little Party Dress, and a mother to three young children.

She has also run educational, inclusion and arts workshops for over a decade.

barriers and defying all odds from day dot.

The disability advocate is a fierce supporter of women's rights, especially those living with disabilities, social justice issues, and even campaigned for the Greens party in the 2020 state election.



Who holds power during pregnancy?

Today I will be discussing the intersections of disability, pregnancy and the subsequent loss of agency that many women with disabilities experience. This will be through the lens of my journey to have my daughter Alessandra.

Barriers to autonomy

Many women with disabilities struggle to have autonomy over their bodies and reproductive rights. Ableism, sexism and the medical sphere converge in a way that ultimately controls their bodies.

In the quest for women's rights, disability rights have largely been ignored. Intersectional feminism is on the rise but the recent publicity of the overturn of *Roe v. Wade* highlight how we are excluded from the conversation. Often, disabled women, particularly disabled women who are black, indigenous, and people of color (BIPOC), are overlooked in these conversations. The intersectionality of disability justice and gender justice must be acknowledged for us to defeat systemic oppression and undermine patriarchal norms.

“We do not discuss how *Roe v. Wade* plaintiff Norma McCorvey was institutionalized, was a ward of the state, experienced extreme trauma throughout her life, and used substances. We fail to address how these issues of autonomy, due process, and control over our bodies that permeate reproductive justice case law and disproportionately affect disabled women. We ignore the ways in which reproductive justice intersects with disability justice.” MARISSA DITKOWSKY Diversity Chair, ACS District of Columbia Lawyer Chapter.

- + Women with disabilities are disproportionately negatively affected by society and the law.
- + Supreme Court Justice Oliver Wendell Holmes, Jr. thought it apt to write in *Buck v. Bell*, “It is better for all the world, if . . . society can prevent those who are manifestly unfit from continuing their kind. Three generations of imbeciles are enough,” in upholding the constitutionality of a Virginia statute authorizing compulsory sterilization of individuals with intellectual disabilities for eugenic purposes. *Buck v. Bell* has never been formally overturned.

Women with disabilities have less reproductive rights

- + Women with disabilities in Queensland have very little reproductive rights. It is currently legal for women with disabilities to be sterilized without their consent. Many young women are placed onto birth control early for the benefit of the family and carers. They find periods too difficult to deal with and are wanting to prevent that person becoming pregnant.
- + This should not be happening without the person making an informed decision for themselves. This is often justified that the person with the disability cannot understand but those assumptions are usually ableist and outdated.

all about
women

we've got this



I had my period stopped

It can be well meaning and innocuous. I experienced this myself despite being a strong self-advocate. I was placed onto birth control when I was 15 by my GP. I was prescribed depoprovera which causes your periods to not come at all. As a result, I ended up staying on it for 5 years longer than is recommended. It failed and I had my period every week for 9 months. I was terribly ill. Long term use can cause infertility and hormone issues.

When birth control is prescribed for us in that risk vs benefit model the side effects are not seen as negative because the view is we would not be having children in the future. The reality is more women with disabilities are having children than ever. You can hear their stories in the book compiled by Eliza Hull called “We’ve got this. Stories by disabled parents”.

Stigma

The assumption is often that women with disabilities cannot and should not have children. There is still a lot of stigma around this. This ultimately informs on women's abilities to control their bodies, whether it is to prevent pregnancy or to get pregnant.

Disability Advocate Fiona Anderson says: "There's a whole stigma around sexual health and [physical] disability. The GP was very shocked when I got pregnant. It was a bit of an awkward conversation, because they just don't expect you to have children, or to want the things that other people have. I remember my GP saying 'no, you couldn't be pregnant, not with your condition'. I had to really prompt them to do a pregnancy test."



Informed decision making

These are serious barriers to women making informed choices about their bodies and family planning. Women with disabilities must be able to visit their GP or gynecologist and discuss the best medical choices for themselves free of judgment or ableism. It is sadly not just attitudes that are a barrier to women being in control of their reproductive health.



Medical care is inaccessible

For women with disabilities sexual and reproductive health care are simply inaccessible. I am sure many people are unaware of that fact.

When we consider somewhere accessible, we might consider if the building has parking, an accessible door and a disabled toilet then the assumption is that is an accessible practice. Access is more than that.

This is me struggling to reach my child in her NICU crib.



Physical barriers to accessing care

Proper access is a broad range of measures.

Consider -

The height of the examination table for transfers and the size of the treatment room.

Equipment so the person can access the treatment. For example, a hoist or slide board.

Pamphlets in large text or brail.

A sign interpreter for someone who is deaf.



The impact of inaccessibility

Inaccessible sexual and reproductive health care has impacted women with disabilities health and wellbeing.

A movement emerged in the United Kingdom and disability advocate Fiona Anderson was the catalyst.

When Fiona, a wheelchair user, tried to book her cervical screening (smear) test at her local GP practice five years ago, she was told the practice did not have the facilities she needed – a hoist – to access screening. However, Fiona, 30, says her GP reassured her: “Your risk of getting cervical cancer is low because you’re a wheelchair user.”

Her change.org petition calling for accessible cervical screening now has more than 109,000 signatures.

Well, you're sexually inactive..

Perplexed, Fiona asked how using a wheelchair could possibly lower her cancer risk, and says the response was: “Well, you’re sexually inactive.” Fiona couldn’t believe what she was hearing. “I’m a mum to two young children!” she says. “Just because I’m in a wheelchair, you cannot assume that I don’t have a sex life. But even people who aren’t sexually active should still have the right to access screening for their own reassurance and peace of mind.”

This stems from the way in which women with disabilities are viewed in society, which overwhelming stems from ableism.

MARISSA DITKOWSKY Diversity Chair, ACS District of Columbia Lawyer Chapter People with disabilities are, generally, deprived of sexual freedom because they are not viewed as sexual beings and concerns about reproduction and parenting ability. Disabled people may also be viewed as hypersexual. For these reasons and due to the general inaccessibility and inapplicability of sexual education to the experiences of disabled people, sexual education is also largely unavailable.

Studies find significant barriers

This experience is not unique. A study into women with disabilities engagement with healthcare services, in this case cancer care,

“found that this population faced significant barriers related to access, including problems getting into clinicians’ offices and using examination equipment, such as tables. Lezzoni found that the mere existence of accessible equipment does not guarantee its usability.¹¹”

A deadly attitude

Research published by [Jo's Cervical Cancer Trust](#) in August found nearly two-thirds of 335 women with physical disabilities surveyed by the charity were unable to access potentially life-saving cervical screening tests, and the picture is even worse for women with learning disabilities or autism.

The 2018 #MyGPandMe [study](#), published by charity Dimensions, found just 19 per cent of women with a learning disability or autism had had a recent smear test – compared to 73 per cent of the general population.

Outdated cultural perceptions

Both pieces of research also found a large number of disabled women come up against the same misconception Fiona described. One in five physically disabled women surveyed by Jo's Cervical Cancer Trust said healthcare professionals had assumed they are not sexually active because of their disability. Dimensions told i: "Outdated cultural perceptions that women with learning disabilities aren't sexually active permeate into GP practices, and drastically reduce patients' access to screenings."

According to Dimensions spokesperson Gemma Jones, who herself has a mild learning disability, this assumption can result in women with learning difficulties not being offered smear tests just because they have a disability – regardless of whether they are sexually active or not.

System overhaul is needed

A systematic review on access to healthcare found that 'disabled people are restricted in accessing healthcare and report less satisfaction' (p 21).⁴ Difficulties in accessing healthcare can be caused by a range of barriers including lack of transport, inaccessible buildings, and intangible barriers, such as lack of disability awareness among healthcare professionals.⁴⁹

Barriers to accessing abortion services

Women with disabilities face the same barriers in accessing an abortion as they do access sexual health care services.

Abortion clinics do not have the level of access and care that women with disabilities require.

Women with disabilities require access to abortions at the same level of non-disabled women.



Children by choice.

This is why the work of Children by choice is so important.

Abortion must be available in every state hospital so that women can access local, affordable, accessible and personalised medical care.

Abortion is medical care.

My Journey

My personally journey reflects what the research states. After a decade on the Depo-Provera and was failing me, unable to safely have a Mirena inserted and the pill unsuitable due to clot risk my ability to protect myself from a pregnancy was seriously diminished.

I experience that same narrative, the one where you are told you will never get pregnant, stay pregnant and in doing so your life is at risk. I grieved that loss. So at 30 years of age when I missed a period over a very busy Christmas period I never considered for a second that I was pregnant. Years of the pill destroying my cycle and a family history of very early menopause I figured I better book an appointment with my GP. When I saw him he was just as dismissive as I was. I would not be pregnant. I took the blood test. He called the home phone two days later.



"I got this frantic call — it was my doctor. He said in this hushed tone, 'Alyce, you're pregnant'. At that point, the world just stopped."

— Alyce



You will need an abortion

The immediate advice was that I needed an abortion. A pregnancy for me had real risks.

"[My partner, the doctor and I] were having a very frank discussion about what I should do," she says.

"[The doctor] said, 'I really think you need an abortion'. That is such a devastating conversation, especially when you're a couple in your thirties and you already have [foster] children.

"I shut down. I didn't talk to anyone. We were in limbo waiting for my first ultrasound."

From the point of conception of my daughter my body existed in limbo.

Despite being an advocate I was unprepared for the barriers and ableism.

I struggled to access medical care.

I could not access the physical examinations and scans. My partner had to lift me everywhere. There was no equipment.

The local hospital refused to see me at a clinic, physically turning me away.

Endured a three week wait to see a obstetrician and have to travel two hours to do so.

Too long to wait to know if I had to be referred for a termination or try to carry my pregnancy.

There wasn't really that ability to enjoy being pregnant, it was just being anxious.

Emotional pain

Every day my stomach grew, my baby flourished and the thought of having to have an abortion felt worse and worse. I just wanted an answer. I was too much trouble, a liability, too complex. I was a woman who needed to access care that no one wanted give.

I had to face my own feelings. I had been always told I could not have children and I experienced grief at the time. I thought I had accepted the reality and gravity of the situation. That did not erase that I had always wanted children.

In the meantime I was living while pretending not to be pregnant.





Physical barriers, travel and costs.

Having to get up early and travel two hours away for weekly scans.

Seek care for my two older children if we were in Brisbane late.

Have to sit in my travel wheelchair for hours at a hospital clinic.

Use public toilets.

Be lifted in and out of my wheelchair for multiple procedures.

Pay for petrol, parking and food.

Drive back to regional QLD at the end of the day. My legs would swell.

I have severe scoliosis and I struggled to lay on the table for procedures, struggled to breathe in a supine position, I could not cope with the speculum and wands, I am small woman. Having my access needs not met was absolute torture and caused me considerable pain. In the end my partner could barely lift me onto the table for them to treat me.

Decision making

Expectations

- + Discussion of risks
- + Options
- + Respect
- + Care plan
- + Book a termination or plan to keep the pregnancy

Reality

- + Ableism
- + Chastised
- + Called irresponsible for falling pregnant
- + Told I should have sought genetic counselling first
- + Power imbalance
- + Asked if my partner was the father

How many able bodied women are spoken to that way?

- + It was at that very moment I felt that power shift. The people who were responsible for arranging an abortion or birthing my child had the power and I had no agency. It was also highly inappropriate as she did not know if I had counselling or what measure I had taken to not get pregnant.
- + “Not all disabled people are permitted to make decisions about their own reproductive rights. Disabled people may be subject to forced sterilization or abortion, or even forced to reproduce. Guardianship may play a role in whether someone can make these decisions—rules are not consistent, although there are typically due process requirements involved in when a guardian can make such decisions. In one case, six-year-old Ashley X’s parents elected to perform oestrogen therapy, bone plate fusion, a hysterectomy, and breast bud removal, claiming she would never develop past the motor and cognitive skills of a three-month-old. The State of Washington eventually found that the procedure was illegal, but these eugenic attitudes remain pervasive.” MARISSA DITKOWSKY Diversity Chair, ACS District of Columbia Lawyer Chapter

Careful, measured advocacy

Countering the argument

- + As the patient I had in depth knowledge of my disability
- + I know the genetic risk factor, it's a 1 in 2 chance of passing my disability on
- + Disease varies in severity
- + My partner and I were not concerned if she had my condition
- + Our other children have disabilities
- + OBGYN was shocked

Previous experiences

- + My parents were advised to undergo painful and invasive testing after my birth
- + The goal was to find which parent had the gene or carried it
- + I was tested as a toddler
- + I have a large scar and muscle weakness where the muscle slice was removed from my bicep
- + My parents had genetic counselling and opted to have no more children
- + I have had a lifetime to decide that I would not repeat what they went through

A life worth living

- + People with disabilities and families of people with disabilities have been fighting this narrative, the ones based on eugenics that encourage abortion and control of people with disabilities.
- + “Additionally, disabled people, particularly women, face increased barriers to accessing reproductive health care and assisted reproductive technology; for example, parents face discrimination based on doctor concerns about parenting, concerns about pregnancy complications, or concerns that a child will be disabled.”
MARISSA DITKOWSKY Diversity Chair, ACS District of Columbia Lawyer Chapter
- + I will note here that the disability rights movement is radically pro-choice. We are fighting the ableism in the system, not asking to regulate abortions. Women with disabilities still need abortions.

Saving Grace

In this period between being unable to have an abortion or support to carry my child to term my mental health suffered.

I refused to talk to or pat my stomach for fear of bonding with the baby. Then one night sat up alone at night, crying and apologising to my child for having to end her life.

It took courage to realise that despite the risks, despite being told that I couldn't bear a baby it was worth trying.

It took the women before me, the brave ones that had a baby despite society saying not to.

"Seeing her on the screen, this gorgeous jelly bean ... in my heart, I knew I had to give it a chance," Alyce says.

"It was absolutely statistically a stupid idea — I was probably going to get hurt during this pregnancy, but seeing her and seeing Brendan's face when he saw our baby ... Even though we were terrified, I had to try."



Trying to reach viability

It was a decision made that went against all expectations of me. It took significant advocacy to be reluctantly supported to try and carry my baby to term.

I had a very stressful period waiting for my child to reach the magic number of 23 weeks and 4 days where she could live outside of the womb.

This made me realise how important access to late term abortion is because if I had gone into respiratory distress before that date where she could survive, saving my life would have been an abortion. When I had Alessandra in 2018 that was not legal.

My body was treated as less capable. It could not fulfil the duty of woman.

- + The remainder of my pregnancy was the constant tests because of the idea that my body would fail. I have had a lifetime of the medical community treating my body like a deficient broken mess. Now I am not ignorant! Having scoliosis, low lung capacity, a short torso and not much space obviously has major risks. As any woman experiences those with pregnancy and it is worse for me. My body was treated as if it could not possibly carry her, that she would fail to grow, that I would go into early labour, that I would miscarry. My body was constantly a site of catastrophising.
- + It was recommended that I have a c-section and that is a sensible choice as well. That is not the issue, to look at the actual risks. It is the way my body was treated like it couldn't grow her, couldn't keep her safe. This female body could not perform what it was designed to do. Yet it did. I had an astoundingly uneventful pregnancy. Boring in fact. Until she grew too big for my height and needed her brought on early.

As an advocate it is my responsibility to bring my community with me. As advocates we pave the way so that other people with disabilities will have the choice.

The statistics for our community are horrific. Women with disabilities have the lowest education, lowest levels of employment, high rates of domestic violence and sexual assault, add to that the state could turn around and deny us our most basic human rights. When Children by Choice approached me to do this conference, I had to do it for disabled women everywhere . We will ensure women with disabilities have full control of their reproductive health in this country.

Turning point

- + For my fight to have my daughter, my most radical act of feminist resistance in this world, the way was already paved for me.
- + Doctors were reluctant to let me continue because there was not a protocol for pregnancy and birth in their view. They were unaware that women with my disability around the world have children. I had to tell them so and I was lucky I had that knowledge.
- + My friend and fellow advocate Fiona Anderson has had not one, but two children and she is as severely affected as me with our condition and shares all my complications.
- + It was not until I shared this information, correcting them, that they would even support my choice to carry her to term.
- + Doctors in the UK respected Fiona's bodily autonomy and supported her through birth.

Meeting people with disabilities in the context of their life, not disability.

- + My team contacted the doctors in the UK and developed a plan for my child's birth.
- + Fiona still experienced ableism like I did. "There's a whole stigma around sexual health and [physical] disability. The GP was very shocked when I got pregnant. It was a bit of an awkward conversation, because they just don't expect you to have children, or to want the things that other people have. I remember my GP saying 'no, you couldn't be pregnant, not with your condition'. I had to really prompt them to do a pregnancy test."
- + Dr Barham-Brown who is a wheelchair user believes doctors' education is at the heart of the problem. "In medical school, you only come across disabled people in the context of their disability; we don't meet them in the context of their general lives. We need to start encouraging doctors to look more holistically at our patients and addressing all of their health needs."
- + It was extremely lucky I met Fiona through the activism of the disabled community. Doctors could not believe someone had already had children and that I personally knew them. Fiona had made history and then I would be in Australia too. A research paper has subsequently been written about me.



I defied all the odds and made it to thirty weeks and 2 days

"My body might not cope, I could pass away. The thought of never meeting my baby and to lose my life and leave my other children without a mother ... all of those things were just looping for me.

"I was laying on the table in the operating theatre. As they sent me to sleep, I just thought, 'I'm laying down my life for her. Please let her live'."

And she did.

"That moment of opening your eyes, and realising you've lived, you've survived ... Brendan's first words to me were, 'She's beautiful'."

Alessandra Grace was just 1.1 kilograms, so we had to wait 10 weeks before taking her home."



Casual discrimination

“Parents face discrimination based on doctor concerns about parenting, concerns about pregnancy complications, or concerns that a child will be disabled.” MARISSA DITKOWSKY
Diversity Chair, ACS District of Columbia Lawyer Chapter.

Insisted on testing my child in the uterus

Scanning to look for defects

During that scan the doctor pointed out, quite shocked, that my child’s spine was straight

The doctors were constantly concerned that my child “would be like you” in overwhelmingly negative terms. One of my midwives got upset and said to me that she “Didn’t like the way they spoke about the baby like that, because if they say that about her, what do they think about you?”. They told me they thought it was quite wrong and that there was nothing “wrong with me”.

Coercion

- + The worst incident I experienced was a fight between my OBGYN team and the genetics department.
- + The genetics department heard I was in the hospital for a procedure and demanded to speak to me. The OBGYN team asked me if I would comply so they would stop harassing them.
- + I had already been forced to consent to having Alessandra genetically tested for my disease but they wanted to test me.
- + They wanted to test me to compare with the original diagnosis and against my child's results. I was not a patient, my child was. I had not been referred to neurology. I did not appreciate being a subject of their curiosity.
- + They asked me to submit to a muscle biopsy. I refused stating my reasons which included that I already have a diagnosis and that I would not want to have another painful, invasive procedure for no reason.
- + He tried to tell me that the procedure was not invasive and only left a small scar. I told him he was wrong. He told me I was wrong. I lifted my sleeve up to show the significantly sized scar on my bicep and surrounding muscle wasting on that limb. I told him I would submit to the genetic blood test nothing more.
- + The doctor became very angry and told me I would be needing the biopsy and he would seek his superior. I told him to get his superior.

No peace, not even during birth

- + The doctor did agree to allow the blood test.
- + They wanted permission to come in and take the blood from me while I was birthing my daughter. My OBGYN team were horrified.
- + After speaking to a friend who is a nurse I felt confident enough to make sure they did not have my consent to enter.
- + My OBGYN team took the blood and carried it out to them.



Genetics avoided me in the halls

After all the ableism I endured under the guise of “we need to know” if your child is disabled, Alessandra smashed all expectations of her. She did better than premature babies in her room and was sent to special care quickly. She was back transferred to Toowoomba in 2 weeks.

She ended up being totally, boringly, able bodied. All the obsession was for nothing.



Equipment for disabled parents

Nothing was accessible. Not the beds, examination tables, scanners.

NICU, Special Care or ward cots were not accessible. There was two “leo cots” for the entire hospital. They adjust down but only to a height for an able bodied woman sitting down.

Women who are blind or deaf need resources and interpreters.

This was me struggling to reach to feed Alessandra in her crib, I was weak from the surgery and trying to reach in from my wheelchair.

We must think about the access needs of all parents.

People with disabilities are still second class citizens.



Flared my disability

I came to the end of my pregnancy journey exhausted and burnt out. Between the travel, the lack of access, the ableism and my 10 weeks in NICU/SCN as a breastfeeding Mum in a wheelchair I was broken and injured.

I had pressure sores, lost use of my right arm and was in pain every day.

The worst part was most of it was unnecessary if we had accessible spaces.



Reforms

Accessible accommodation for patients. Even Ronald McDonald house did not meet my access needs.

Covering of financial costs.

Appropriate and evidence-based decisions making

Access to local services

Accessible services from clinics to hospitals.

Abortion in public hospitals

Steps to ensure all gynaecological, abortion and pregnancy care is accessible

End all control of disabled women's bodies.

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Miracle baby's thriving

Girl born to woman with severe physical disability

TOM GILLESPIE
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ALESSANDRA Nelligan-Cooke could fit in your hand when she was born 10 weeks premature a few months ago. Now she's so heavy and healthy that her mother Alyce struggles lifting her up.

"She just hit 5.1kg, which we were stoked at," Ms Nelligan said.

The 10-week-old Toowoomba baby celebrated her first Christmas with parents Ms Nelligan and her fiancé Brendan Cooke.

Alessandra's mother entered the record books in July when she became the first woman with minicore myopathy in Australia known to give birth.

The rare and complex muscle-wasting disease meant Ms Nelligan's final few weeks carrying Alessandra were painful, with doctors performing a caesarian at 30 weeks.

"I couldn't get any larger, and her growth slowed. I'd pushed the limits of my physical size," she said.

But the 32-year-old said after a few nervous weeks in the hospital, she realised her daughter was as healthy and happy as any other baby.

"It was so nerve-racking (taking her home) - I didn't

sleep the first two days, but she was happy and didn't have any problems," Ms Nelligan said.

"She's such a happy and funny bubba. She's always smiling and laughing. You couldn't meet a happier baby."

Ms Nelligan, a fierce advocate for the rights of those with disabilities, said the enormity of her achievement to simply give birth dawned on her several weeks later.

"Every so often, it just hits you. I look at her and realise I did it," she said.

"It makes you realise this is something extraordinary.

"We have a long way to go, but when people go out and do this, it breaks the stigmas to help people who come afterwards. It normalises this for disabled people."

Ms Nelligan and her daughter defied doctors throughout the pregnancy and after Alessandra's birth.

"I just pinch myself - even my GP was shocked," she laughed.

“ SHE'S SUCH A HAPPY AND FUNNY BUBBA. SHE'S ALWAYS SMILING AND LAUGHING.

ALYCE NELLIGAN




MIRACLE BABY: Alessandra Nelligan-Cooke, who was born 10 weeks premature, is healthy, much to the delight of her parents Brendan Cooke and Alyce Nelligan (pictured).
Photo: Contributed

Baby Alessandra Nelligan-Cooke just days after being born premature. She weighed just over a kilogram.
Photo: Erica Henderson

Thank you.

All the wonderful people in the system it cannot make up for the fact that women existing in a space where they are stripped of their rights because they are disabled.

Not only do we need to normalise people with disabilities having children but we have to fight so that women with disabilities can choose what is right for them and their bodies.

Thank you for having me today.



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