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Re(al)   
Productive  
Justice

GENDER AND DISABILITY

# Pregnancy & birth toolkit



OLLSCOIL NA GAILLIMHE  
UNIVERSITY OF GALWAY

CENTRE *for* DISABILITY  
LAW & POLICY

**W**  
welcome



## Table of Contents

<b>About this toolkit</b> .....	<b>1</b>
<b>Pregnancy and birth</b> .....	<b>3</b>
<b>Top Tips</b> .....	<b>4</b>
<b>1. General accessibility tips</b> .....	<b>4</b>
Accommodating disability access needs .....	4
Making appointments .....	5
Attendance of support person at appointments .....	6
<b>2. Before pregnancy</b> .....	<b>7</b>
Pre-pregnancy consultation .....	7
<b>3. During Pregnancy</b> .....	<b>8</b>
Confirming the pregnancy.....	8
The booking appointment.....	8
Options for care in pregnancy and birth .....	9
Assistive devices and equipment .....	10
Scanning .....	11
Antenatal classes.....	11
Birth preferences.....	11
<b>4. After pregnancy</b> .....	<b>12</b>
Post-natal check-ups .....	12
<b>Discussions about infant feeding</b> .....	<b>12</b>
Pregnancy loss.....	13
Perinatal mental health.....	13
<b>5. Case study: Amy</b> .....	<b>14</b>
<b>6. Resources</b> .....	<b>15</b>
Resources for fertility, contraception, pregnancy and loss .....	16



## About this toolkit

The Re(al)productive Justice project is about disabled people and reproductive justice. Reproductive justice is about the choice to have a child, the choice not to have a child, and being properly supported in those decisions. Disabled people should be able to make decisions about having children, to make choices about not having children, and to be properly supported in those choices. However, many barriers exist which prevent disabled people from having the same choices as everyone else. Disabled people have a right to access medical, social work and legal services related to making decisions - and having their decisions respected - around pregnancy and birth. Services should be designed and delivered so that they meet the needs of everyone who needs to access them.

## Who is this toolkit for?

The Pregnancy and Birth Toolkit is for professionals who provide services connected to pregnancy and birth in Ireland. It can be used by a wide range of professionals working in the medical, social work and legal sectors.

## What kinds of disability does it cover?

Our understanding of disability follows the ethos of the UN Convention of the Rights of Persons with Disabilities to include “those who have longer term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation of society on an equal basis with others” (UN, 2006). We consider this statement an open-ended inclusive approach to the question of ‘who counts’ as disabled.

The toolkit is designed to be relevant to a wide range of disabilities, including, but not limited to people with chronic or long-term illnesses, people with a physical, sensory, and/or intellectual disability, people with experience of mental health services (including those who identify as survivors of psychiatry), the d/Deaf community, autistic and neurodivergent people, and those who do not identify with any label or diagnosis but who have experienced discrimination because they are viewed by others as disabled.

## What topics are covered in this toolkit?

This toolkit provides information and practical tips for practitioners who support disabled people in making decisions and accessing services related to pregnancy and birth. The toolkit uses quotes from our Oral Histories and Key Informants experiences to set the context for each issue. Case studies allow you to reflect on your own practice. A non-exhaustive list of Dos and Don'ts will guide you through each issue. Finally, a list of resources that might be useful in your practice is included.

### Who made this toolkit?

The toolkit was developed by researchers at the Centre for Disability Law and Policy, University of Galway, as part of the Re(al) Productive Justice project. We benefited from collaboration with health, social care and legal professionals and with our stakeholder and ambassador group which includes a range of disabled people and health, social care and legal professionals.

### Where can I find out more?

This guide is part of a series produced by the Re(al) Productive Justice team. The full list of toolkits includes Parenting, Pregnancy and Birth, Fertility and Contraception, and Abortion, as well as another short guide, the Communication Guide.

For more information you can visit our dedicated Re(al) Productive Justice project website:

<https://www.universityofgalway.ie/centre-disability-law-policy/research/projects/current/real>.

To find out more about the research conducted on the reproductive experiences of disabled people in Ireland, you can read our oral histories which have been archived at the Digital Repository Ireland:

<https://doi.org/10.7486/DRI.ws85q6171>.

We are also publishing a book on the findings of our research, which will be available in 2023.

If you have questions not answered by this toolkit, please email [realproductivejustice@nuigalway.ie](mailto:realproductivejustice@nuigalway.ie).

## Pregnancy and birth

Disabled people need pregnancy and birth services as much as non-disabled people. Despite this, pregnant disabled people are often treated by professionals as if they should not be pregnant and should not be assisted to become pregnant at all. Ableist assumptions see the pregnancies of disabled people categorized as inherently riskier. They are regularly denied access to midwifery-led care and home-birth, and disabled people are often subject to disproportionate interventions in their pregnancies compared to the experiences of non-disabled counterparts. Disabled pregnant people who have attempted to refuse consent to particular procedures have reported feeling threatened when health and social care professionals reframe their refusal of intervention as lack of care for the baby, calling the disabled person's ability to parent into question. Others have reported having to explain their impairment and justify their decisions repeatedly throughout the pregnancy journey. The journey is often a precarious one, as disabled pregnant people carefully navigate their often limited care choices, attempting to have their needs met while avoiding the worst of ableist assumption about them. Health and social care professionals can help remove the barriers endured by disabled pregnant people by ensuring their own practice doesn't perpetuate negative assumptions and by ensuring accessibility in all maternity settings.





## Top Tips

### 1. General accessibility tips

#### Accommodating disability access needs

There are many ways in which providers can make their services more accessible for disabled people. Be aware that every disabled person has different access needs, and something that works for one person may not work for another person (even if they have the same disability). It is important to explain what you do provide before you ask a disabled person what else they might need.

Even if someone's access request seems unusual or you have never received that kind of request from someone with that disability before, do not question whether they 'really need' what they have asked for. Instead, work as best you can to provide the request or check with them if there is an alternative solution that will work. While an individual's access needs can fluctuate, this does not mean that they do not really need the access they have requested. For example, depending on the individual's condition, they may walk unaided some days but use a wheelchair or crutches on other days. If they ask for wheelchair access, but arrive without a wheelchair to a certain appointment, this does not mean they will never need wheelchair access in the future. Access to a wheelchair should continue to be provided unless the person says they no longer need it.

In referring the person on for other forms of care or treatment in pregnancy, it can be helpful to pass on information about the person's access needs to other practitioners so that the person does not face further barriers to their care. Check with the person how they would like their access needs communicated when information is passed on to another practitioner or service – they may not want the full details of their medical history disclosed and it may not be appropriate to do so.

#### Do :

- Provide specific information in advance about how accessible your practice is.
- Enable people to make appointments in different ways (e.g., phone, online).
- Ask people making appointments if they have any access needs.

#### Don't :

- Say 'our premises is fully accessible' without providing specific details
- Question the person's access need or disability
- Assume the person will be accompanied by a personal assistant or supporter who can compensate for an inaccessible service



*"I think there is physical discrimination in that the building isn't very wheelchair friendly. So, for example, we have, I don't know how friendly it would be if you were blind or deaf because it is quite, I don't know how it would work with that. We have for example, a ramp at the front door. We, I cannot think where our wheelchair accessible toilet would be. I actually have no idea where it is now that I am thinking about it. We have other, another building around the corner which would be used for breastfeeding education postnatally and for antenatal classes, pre-covid, which are all online now. And it has a wheelchair accessible lift so that women can access the building, because it is up five steps. But the lift is the despair of most of the staff at the hospital because we are constantly rescuing people who have been abandoned when the lift breaks. So that isn't fantastic."*

- Keira, OB-GYN

## Making appointments

When a person is making appointments for pregnancy-related care and discloses a disability, the provider should explain what supports are available for disabled people during appointments. This information should also be added to the provider's website so that disabled people will know in advance before booking an appointment what they can expect.

Example of website accessibility information: "At this practice, we have step free access to all consultation and waiting rooms for our patients. We can arrange sign language interpretation for patients who need it but we generally need 48 hours' notice in order to book an interpreter. We welcome patients with assistance dogs. Patients can make appointments by telephone or using our online booking form."

It is important to have a number of different ways for people to make appointments. Email or text options provide access for disabled people who cannot make appointments by phone, including Deaf people. On appointment forms, or as part of the general response when people enquire about appointments, it can be helpful to ask, 'do you have any specific access needs we can help with?' Many people do not identify as disabled but will answer a question about access needs.

### Do:

- Provide specific information in advance about how accessible your practice is.
- Enable people to make appointments in different ways (e.g., phone, online).
- Ask people making appointments if they have any access needs.

### Don't:

- Say 'our premises is fully accessible' without providing specific details.
- Question the person's access need or disability.
- Assume the person will be accompanied by a personal assistant or supporter who can compensate for an inaccessible service.



*"You know, I need a hoist. So, when the consultant said to me that I needed to go into a chair. I said, 'Well. I can't get into that chair; I need a hoist.' And we made two appointments and the hoist wasn't there at each appointment. And so, I ended up kind of like, you know, because I was quite concerned about it, you know. So, I ended up having to move to the edge of my wheelchair and open my legs and a nurse on each side, it was so undignified. It just wasn't dignified at all."*

- Maureen, physical disability



*"We do for say a pregnant woman we do what is called a booking visit at a very early stage of their pregnancy where you ask them everything that has ever happened them, before, since. But you don't mandate disclosure of particular things. So, you offer questions, but somebody doesn't have to disclose it. And I suppose, you could say maybe that's not the time when they think it is relevant, it is more as the pregnancy moves on and maybe it could be hard for people to disclose it. So maybe you do need to be more enabling, have notices up or maybe mention it at ante natal classes."*

- Kai, OB-GYN

## Attendance of support person at appointments

Some disabled people may wish to bring a support person with them to appointments during their pregnancy. The supporter may be needed to facilitate effective communication between the person and the practitioner, to support the person to process the information received at the appointment afterwards, or to provide emotional support. The support person may be a friend or family member, or a paid supporter such as a personal assistant or key worker. Attendance of supporters at appointments should be facilitated by health professionals. Even during public health emergencies, such as the COVID19 pandemic, HSE guidelines maintained that disabled people should be permitted to have support people accompany them to health appointments (including in pregnancy).

However, it is vital that practitioners always speak directly to the disabled person about their pregnancy, not to their supporter. If a practitioner has concerns about supporters exerting pressure or undue influence on the disabled person to make decisions related to pregnancy and birth, they should try to communicate with the disabled person alone to ascertain if the person is providing informed consent. The boundaries of the support role should be discussed at the first appointment. A supporter may be assisting the disabled person to understand information provided, but does not have any legal authority to provide consent on the person's behalf (unless the pregnant person is a ward of court and the supporter is the Committee of the ward). While supporters or interpreters may assist with communication, it is the clinician's responsibility to ensure that jargon-free, easy to understand information is provided, and the clinician must satisfy themselves that the person is giving free and informed consent to any treatment or intervention and not rely solely on the supporter to ascertain that consent is provided.

If a Deaf person needs a sign language interpreter, it is the responsibility of the relevant GP or maternity service to arrange interpretation (see here for how to book an in-person interpreter: <https://www.irishdeafociety.ie/interpreters/booking-an-interpreter> and here for booking a remote or online interpreter: <https://slis.ie/iris> ). It is vital that where a person has asked for sign language interpretation it should be provided to them at every appointment. Deaf pregnant people should not have to rely on family members to interpret for them during pregnancy care as this can violate their privacy. Healthcare staff with basic ISL skills are not a replacement for a professional, qualified, ISL interpreter. Services should be aware that Deaf people from Northern Ireland may need British Sign Language interpretation, and Deaf people from other countries also may not have sufficient ISL to communicate. It is essential that the service finds out exactly what type of interpreter the person needs so that it can be arranged in advance.

### Do:

- Allow a supporter to attend if requested by the disabled person.
- Continue to communicate directly with the disabled person, not their supporter.
- Provide access to the appropriate sign language interpreter, where requested.

### Don't:

- Ask family, friends or service colleagues to interpret in place of a qualified interpreter.
- Allow anyone other than the disabled person to consent to or refuse treatment.



*"I had a case this week where there's a mum who's pregnant, now she's very early pregnant I think she's eight weeks... the staff member came to me and said the mum was saying, 'Oh I don't feel at the appointments I'm taking in all the information that they're giving me', and I had said to him, well go away, link with the social work department in the hospital and see what supports can be given to her. Because of COVID she can't have a support person in the hospital or can they make allowances for her to*

*have a support person in the hospital or can the social worker in the hospital support her to ensure that she's – getting all the information that she needs and is understanding it. So he went away and did that and then the social worker came back to him to say that she felt that himself and herself should make a joint referral to Tusla, a pre-emptive referral to Tusla just in case. And I lost my rag obviously and said to him there is no way in the world you are going to do a joint Tusla referral, where are the child protection concerns? That mother is engaging with the hospital, she is seeking supports and I felt, now obviously I've no evidence but I felt that the only reason why she was making a Tusla referral is because that mother had a disability which is absolutely disgraceful."*

- Kara, Social worker

## 2. Before pregnancy

### Pre-pregnancy consultation

Some disabled people will want the opportunity to discuss questions they have about pregnancy and their specific health or accessibility needs before they start trying to get pregnant. When providing information about possible side effects of medication or treatment, health professionals should not assume that disabled people do not ever plan to become pregnant. Instead, they should ask the person whether they plan to become pregnant and if this information is relevant to their treatment options.

In offering and providing pre-pregnancy consultations for disabled people it is important to remain non-judgmental about the person's decisions relating to pregnancy and birth and to fully explore any questions or concerns the person may have, including referring the person to other specialists if desired for further consultation.

#### Do:

- Provide non-judgmental care.
- Explain the potential impacts of treatments on the person's fertility.
- Offer further referrals or to find out more information if the person has specific concerns that you are not equipped to address.

#### Don't:

- Assume disabled people do not plan to become pregnant.
- Withhold information about possible side effects of medication on pregnancy.
- Dismiss the person's concerns about the health impact of a potential pregnancy.



*"Other times where, occasionally we see a good bit of where GPs will stop treatment for their mental health condition inappropriately in the community. I suppose you could argue what is going on there is a nervousness about litigation, I think it would be excessively harsh to frame it all as prioritising the baby over the mother but you could argue that there is an element of people are very concerned about the baby and see the mothers mental health as less important. I think there is more a concern about being sued if there is an adverse outcome for the child, so doctors are cautious and stop everything."*

- KI06 Psychologist in maternity services.

### 3. During Pregnancy

#### Confirming the pregnancy

It is common for pregnancies to be confirmed by the person's General Practitioner. Depending on the person's particular living situation (e.g., residential disability services, living at home with family), they may need additional support to attend the appointment to confirm the pregnancy. For example, some disability services due to their religious ethos, may not provide support for disabled people living in that service to attend appointments related to reproductive healthcare. Some disabled people living at home may not have family members they are comfortable to support them in attending an appointment to confirm a pregnancy.

#### Do:

- Congratulate the person on their pregnancy
- Offer to discuss any questions or concerns they may have
- Make available information on how access needs are met within the practice and check what additional needs the person may have when booking the appointment

#### Don't:

- Assume the person wants to terminate their pregnancy.
- Use technical or medical jargon to describe the next steps in the pregnancy.
- Disclose information about the person's pregnancy to family members or disability service providers without the person's informed consent.



*"And very soon was asking where was my carer? So, of course I said, what carer you know. 'Do you not have a carer that takes you know care of you at home?' I said, 'Absolutely not I'm an independent person, I run the household' ... I dropped the bombshell, 'Oh my goodness, daddy is blind too'. Well, I could nearly hear her calling social services."*

- Nadine, blind



*"Yeah, I can think of one example of a lady who, now she actually got pregnant prior to me joining the practice but I just looked at her notes and she would come in with vague symptoms and was asked was there any chance that she could be pregnant? She said, 'absolutely no' but her pregnancy test was positive. She has got a genetic disability and unfortunately, her son also has it."*

- Donal, Rural GP

#### The booking appointment

For many pregnant people, this booking appointment - which takes place between 8-12 weeks gestation of the pregnancy - is the first point of contact with the maternity hospital or community midwifery team that will be providing much of the person's care. This is a crucial time to be aware of a disabled pregnant person's access needs and to ensure that the care provided throughout the rest of the person's pregnancy and birth is accessible for them. As booking visits are usually made upon referral from the pregnant person's GP, the GP should advise the hospital or centre of the relevant person's access needs as part of the referral. This will ensure that when the pregnant person is notified of the appointment (e.g., by phone call, text message, email or letter) that the communication method used is one that is accessible to the person. For example, sending a printed

letter to a blind person who cannot read it is not an appropriate method of communication and may result in the person missing appointments or vital information about their pregnancy care.

All of the points covered above in the *Making Appointments, Attendance of Support Person at Appointments* and *Accommodating Disability Access Needs* must be reviewed to ensure that all aspects of the service will be accessible upon arrival for the pregnant person. Consider in particular the information that is provided to patients at the booking appointment – are alternative formats available that would be accessible for this person? Make sure to source these in advance of the appointment so that disabled people can leave with the same information and resources as all other pregnant people. Also think about the waiting area for the booking visit and any sensory issues that may arise for disabled people - for example overcrowded areas, bright artificial lighting, a warm and stuffy environment - and assess whether alternative arrangements can be made to accommodate the person's access needs.



*“I mean I hated going in, I hated it. But you go in there because you need someone to check your baby, so you stay. But I mean the amount of times, every time, I wanted to run out. Like half an hour, it’s bright, it’s noisy, people are all close by you. And so I’d spend all my time scripting what I was going to say. Once you got over the initial few appointments and you kind of knew the drill, you script what you’re going to say because you have a fair idea. Do the pee in the cup, talk to this person and they prod around a bit. Then you leave. Get your next appointment. So, I find the environment severe... like, that has severe impact on me, but I actually think that... for a couple of weeks afterwards that would have a severe impact on me physically probably as well as mentally.”*

- Lexie, neurodivergent

### Options for care in pregnancy and birth

Options for care in pregnancy and birth must be fully explained in an accessible manner to ensure informed consent. For example, this might require the provision of information in an ‘Easy to Read’ format (see here for a guide on making information ‘Easy to Read’: <https://inclusionireland.ie/easy-to-read>).

In general, pregnant people in Ireland have options for private or public care (and semi-private care for those in Dublin maternity hospitals). Providers should not assume that disabled people will opt for any specific kind of care and should provide information on all the available choices. Not all disabled people have high-risk pregnancies and disabled pregnant people should not be automatically placed in the high-risk category, according to the Stratification of Clinical Risk in Pregnancy Guidelines from the HSE: <https://www.gov.ie/en/collection/716603-national-clinical-guideline-no-23-stratification-of-clinical-risk-in>.

Depending on the clinical risk in this particular pregnancy, disabled people may have a range of options for pregnancy care – ranging from normal risk (supported care), medium risk (assisted care) and high risk (supervised care). Each of these options must be fully explained to the disabled pregnant person and the implications for who will provide the care should be fully discussed (e.g., GPs and midwives in supported care, with more intervention from consultant gynaecologists and obstetrics in assisted and supervised care).

Options for home and hospital births should also be discussed with disabled people in a non-judgmental manner. Providers should be aware that some disabled people, due to prior medical trauma or as survivors of sexual abuse, may need specific kinds of pregnancy care, and this should be fully respected, while communicating the relevant clinical risks to the pregnant person. Disabled people must be presumed to have capacity to make decisions about all aspects of their care during pregnancy and birth, regardless of their specific condition or its perceived severity.

### Assistive devices and equipment

Disabled people's access needs may change during pregnancy and after birth, so it is vital to discuss what new assistive devices and equipment they may require or what adaptations may be possible to their existing devices and equipment. For example, the additional weight gained in pregnancy may mean that the person's mobility devices (wheelchairs, walking frames etc) need to be changed or adapted to accommodate this. Ask the person if their needs might change during pregnancy for the devices or equipment they currently use. Check in advance what equipment is available in the hospital, clinic or surgery where the person will have ante-natal or post-natal appointments, and give birth. Show the person what equipment and devices are available and check if these will meet their needs or if new equipment needs to be ordered so this is done in plenty of time before the birth.

Following the birth, equipment used for the child must also be accessible for the disabled parent (discussed further in the parenting toolkit). Some examples include:

- Height-adjustable or lower infant changing tables which allow a person using a wheelchair to access them without having to stand.
- Prams or buggies that can be adapted to connect to or accommodate the person's wheelchair or mobility aids, or to be safely used by someone with a guide dog.
- Slings and infant carriers that can be used by someone with only one arm or hand.
- Cots with easily removable sides so that a person in a wheelchair does not have to stand to transfer the child in and out of the cot.

As part of discussions about devices for safe infant carrying, sleep and changing, providers can conduct research with, or on behalf of, the disabled pregnant person about what equipment might be accessible for them. You can see some ideas here: <https://disabledparenting.com/welcome-to-the-disabled-parenting-project-community/how-to-videos/> and here: <https://lookingglass.org/wp-content/uploads/Baby-care-products-chart-TLG-9-2016-1.pdf>.



*"I'd love to see that you know, really places where it's easy to go to find out about the equipment. Like you just can't... Like if I now, even now still know like someone to tell me about the most accessible equipment. You know, it took me ages to research the buggy, the car seats you know. There's so many of them that just won't suit me. I also think you know in my hospital; I would have you know; I'd love to see sometimes a disabled member of staff working there who then might think of things from my perspective, you know."*

- Claire, physical disability

## Scanning

Most pregnant people are offered at least two scans, one at 12 weeks to accurately date the pregnancy, and one at 20 weeks, often known as the anomaly scan. It is particularly important to ensure that the scanning service is accessible for the pregnant disabled person and that a support person is permitted to attend if requested in order to ensure the scan is conducted in an accessible manner with clear communication for the disabled person. If the person has to sign a specific consent form for scans, the form should be available in an accessible format for the person. Examples of differently accessible formats include scannable pdfs for blind or visually impaired people who use screen readers or Easy to Read versions which may be preferred by people with intellectual disabilities.

When sharing information about the findings of the scan, it is important to communicate in a clear and non-judgmental manner with the person. Do not assume any particular reaction if anomalies are detected – as with all pregnant people, depending on the nature of the anomaly, some disabled people will not be concerned about the anomaly, and others may be very upset. Open, honest conversations are vital here – without sharing any inaccurate information about what life might be like for a person with a certain condition after birth. Providers can offer to link the person with peer support, through contacting the relevant Disabled People's Organisations. It is always preferable to link the pregnant person with organisations of adults who have the relevant condition where these exist – rather than support groups of non-disabled parents whose children have those conditions.

## Antenatal classes

It is vital that ante-natal classes offered to pregnant people are adapted to make them accessible to disabled people. When referring a disabled person for ante-natal classes, you can ask those responsible for running the classes to make them accessible for this person's needs. Trainers responsible for providing parent education classes within maternity services should check with the disabled person in advance how the class can be made accessible for them. This may include ensuring that any leaflets distributed during the sessions are available in accessible formats (e.g., electronic or Easy to Read versions), any diagrams used are fully described in a manner accessible for blind and visually impaired people, or models (e.g., of the reproductive system or foetus in utero are tactile and can be held or examined by blind or visually impaired people as an alternative to describing a diagram). Where online classes are available or where videos are used during training, providers should check if real-time captioning (not just relying on AI captions within applications like Zoom or Microsoft Teams) or sign language interpretation is needed to make these aspects accessible to disabled people.

In designing accessible ante-natal classes, just as in conducting disability access audits of services or practices, it is a good idea to invite disabled parents to contribute and share what would have made the class more accessible for them. As with the involvement of other professional staff, disabled people should be paid for any contribution they make to redesigning classes or training materials. A good place to start is by contacting Disabled People's Organisations (listed above) to find out who may be interested in re-designing ante-natal classes or auditing them for disability access.

## Birth preferences

Many pregnant people, including disabled pregnant people, may write down their preferences for care during birth, which must be considered by healthcare staff during labour and birth. Not all preferences or requests made by disabled people can be facilitated especially in situations of medical emergency; however, it is important that birth preferences of disabled people, as with all pregnant people, are respected as much as is possible. Following full commencement of the Assisted Decision-Making (Capacity) Act 2015 (estimated June 2022), individuals may create an Advance



Healthcare Directive which contains legally binding refusals of certain treatment or medical interventions during pregnancy and birth. Where advance directives have been validly made, they will be legally binding and must be respected.

## 4. After pregnancy

### Post-natal check-ups

Following the birth, there are a number of post-natal check-ups which can be carried out in different settings: in hospital, GP surgeries or in the person's home by midwives and public health nurses. It is important that these are all carried out in a manner that is accessible to the disabled person, and respectful of their dignity and bodily integrity. As with all decisions in the context of pregnancy and birth, it is vital to recognise that the disabled person is the expert on their own body/mind, and to take seriously any physical or mental health concerns the person raises. At the same time, as will be discussed further in the parenting toolkit, these check-ups should be a support to the person and should not be distressing or lead the person to feel that they are either not believed or over-surveilled by healthcare professionals.



*"...so, the public health nurse was a bit kind of you know, kept on and on and on at me, kept coming to the house you know going, no, no, he's not talking, he's not talking, this isn't right, so again I was showing her the literature, I was showing her everything that I had that he will talk and he'll be fine. So they sent him to a psychologist, counselling like and I was really angry because they wouldn't believe me, I was his mother, I had done my homework, I knew what I was talking about, I had carried him you know he was my child that I knew, I wasn't concerned, there was nothing wrong with him, you know it was about language development and you know he was three/four years of age, he was going to pick up language you know the same as other hearing kids would, he'll be fine but the fact that the public health nurse wouldn't listen to me and that was something that really, really angered me and just made me very, very upset that you know that I was showing them the proof and they wouldn't get it."*

- Teresa, Deaf parent

### Discussions about infant feeding

During the course of the pregnancy, discussions about infant feeding and the disabled person's plans in this respect will be had by different professionals within maternity services. It is essential that accurate, non-judgemental information is provided and that the disabled person's plans for infant feeding are respected. It should not be assumed that pregnant disabled people cannot or do not want to breastfeed, or that it not be safe for example for a disabled person with a limb difference or mobility impairment to breastfeed.

Rather, creative and flexible solutions should be developed with the person – including trying different or unconventional feeding positions, involving occupational health and physiotherapists where appropriate, and ensuring that they can co-ordinate with lactation consultants and other breastfeeding supports. When making referrals to breastfeeding classes, support groups or services, providers should make sure that the meetings of groups and provision of services are accessible for the person being referred and encourage services to make adaptations where required to meet the person's needs.

## Pregnancy loss

As for non-disabled people, pregnancy loss can be devastating for disabled people and it is vital that disability-sensitive supports are offered to the person at this difficult time. Ensure that any information leaflets and support services (e.g. Bereavement Clinical Midwife Specialists, counselling services and support groups) are made accessible to the person (including description of any diagrams for people who are blind/visually impaired, information provided in Easy to Read formats may be needed for people with intellectual disabilities): <https://pregnancyandinfantloss.ie/> Consider commissioning videos in Irish Sign Language and videos explaining in plain English what supports are available to those experiencing pregnancy loss (remember to add captions for Deaf/hard of hearing people).

Do not assume that the pregnancy loss has occurred due to the person's disability. Offer the person the opportunity to discuss any questions they may have about the causes of pregnancy loss, and any concerns they may have if they become pregnant again. Connect with Disabled People's Organisations to ascertain if there are any peer support groups for people with that specific disability (or disabled people in general) to talk about pregnancy loss, if the person would find this helpful.

## Perinatal mental health

Disabled people may wish to access perinatal mental health services during pregnancy or following a birth. It is important to ensure that disabled pregnant people have access to appropriate mental health supports in their community throughout the pregnancy and after the birth. Most disabled people who choose to access mental health services during pregnancy and after birth will want to do so while living at home and staying connected to their existing social networks and supports, rather than using in-patient services. It is vital that all involved in the person's pregnancy care (from primary care to maternity services) are sensitive to the need for mental health support and do not make assumptions about the person's ability to parent if they request support to manage their mental health.

Innovations developed during COVID-19, such as the Attend Anywhere video-enabled mental health care will hopefully continue to provide this option. It is important to ensure that perinatal mental health care provided can accommodate any other disabilities the person may have (e.g. sensitivities to certain kinds of sound and light or other environmental factors for neurodiverse people) and the option to access services and supports remotely may also be essential for some pregnant disabled people.

## 5. Case study: Amy

Amy has an intellectual disability. Her mother, Mary, makes a GP appointment because she thinks Amy may be pregnant. Both women enter the consultation room when Amy is called. The GP explains to Mary that Amy needs to provide a urine sample. When they return with the sample, the GP confirms Amy's pregnancy and asks Mary whether Amy wants to continue with the pregnancy.

What went wrong here?

Suggestions:

- When the appointment was made no questions were asked about access for Amy.
- The GP never asked Amy if she was ok with having her mother present.
- The GP should have spoken directly to Amy, not her mother.

What should a practitioner do if they are concerned about a disabled person being pressured to make certain decisions during pregnancy?

## 6. Resources

Options for referral if there are concerns about the disabled person's rights not being respected include:

### Independent advocacy

Practitioners supporting pregnant disabled people in any capacity should also be able to support individuals to make a complaint if they wish to do so – the advocacy options below are additional supports for people who wish to access independent support for this process.

- The National Advocacy Service offers free, independent advocacy to support disabled people in vulnerable situations including those isolated from their communities with few natural supports: <https://advocacy.ie>.
- The Patient Advocacy Service assists individuals to make complaints about experiences in acute public hospitals, which includes maternity hospitals. Telephone: 0818293003; web: <https://www.patientadvocacy.ie>.
- Decision Support Service: <https://decisionsupportservice.ie>.
- Free Legal Advice Centre: <https://www.flac.ie>.

### Disabled People's Organisations

Organisations run and controlled by disabled people (known as Disabled People's Organisations (DPOs) and different from disability service providers) can often identify possible peer support networks for disabled people. These include:

- Disabled Women Ireland aims to be a national voice for the needs and rights of self-identified women and non-binary/genderqueer/gender non-conforming people with disabilities and a national force to improve the lives and life chances of people with disabilities: <https://www.disabledwomenireland.org>.
- Disability Power Ireland is a grassroots, cross-impairment DPO whose mission is to enhance the visibility and inclusion of the disabled community by focusing on the arts and culture as powerful vehicles for changing public perception about what it means to be disabled: <http://disabilitypride.ie>.
- Independent Living Movement Ireland aims to ensure that disabled people achieve independent living, choice and control over their lives and full participation in society as equal citizens: <https://ilmi.ie>.
- Irish Deaf Society seeks to achieve and promote the equality and rights of Deaf people in Ireland: <https://www.irishdeafsociety.ie>.
- Neuropride Ireland aims to create a community where neurodivergent (ND) people can connect, share their ideas and experiences, and be proud of who they are: <https://www.neuropride.ie>.
- National Platform of Self Advocates is a DPO run by people with intellectual disabilities for people with intellectual disabilities which aims to be the nationally recognised voice on policy and issues affecting the lives of people with intellectual disabilities: <http://thenationalplatform.ie>.

Be aware that these organisations are often run by unpaid volunteers and may take time to respond to requests for individual support

### Resources for fertility, contraception, pregnancy and loss

As with any pregnant person, if a practitioner is concerned about trauma and abuse then appropriate referrals for support can be made. However, it is important for practitioners to check before making a referral whether that service will be accessible to your patient. It is possible to check the accessibility of a specific service without disclosing personal or identifying information about a particular disabled person.

- HSE resource on domestic violence and abuse: <https://www2.hse.ie/wellbeing/mental-health/domestic-violence-and-abuse.html>.
- Association for Improvement of Maternity Services Ireland (AIMS): <http://aimsireland.ie> .
- Leanbh mo Chroí is a support network of bereaved parents who received a fatal diagnosis during pregnancy: <https://lmcsupport.ie>.
- The National Infertility Support and Information Group (NISIG): <https://nisig.com>.
- Links related to becoming a parent if you have a disability (NI Direct): <https://www.nidirect.gov.uk/articles/becoming-parent-if-you-have-disability>.
- Féileacáin is a not for profit organisation that provides support to anyone affected by the death of a baby during or after pregnancy. <https://feileacain.ie>.
- The Norah Fry Institute has a range of online resources to support parents with intellectual disabilities through pregnancy and parenting: <http://www.bristol.ac.uk/sps/wtpn/forparents>.











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