

Re(al) 
Productive
Justice

GENDER AND DISABILITY

Fertility & contraception toolkit



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CENTRE *for* DISABILITY
LAW & POLICY

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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 fertility and contraception. 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 Fertility and Contraception Toolkit is aimed at professionals working in the medical, social work and legal sectors who provide services connected to fertility, assisted human reproduction, contraception and sterilisation.

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 fertility and contraception. For clarity, this toolkit is divided into two parts – *A: Fertility and Assisted Human Reproduction* and *B: Contraception and Sterilisation*. 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 go to find out more?

This toolkit is one of a series produced by the Re(al) Productive Justice team. The full list of topics covered includes Parenting, Pregnancy and Childbirth, Fertility and Contraception, and Abortion, as well as two short guides, the Communication Guide for Health and Social Care Professionals and the Know Your Rights guide aimed at disabled people and people who experience discrimination in accessing services because of their physical or communication access needs.

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

A. Fertility and Assisted Human Reproduction (AHR)

Top Tips

1) Provision of Information

Due to gaps in provision of sexual health education and the role of religious influences in disability services, it cannot be assumed that all disabled people are knowledgeable about fertility and assisted human reproduction. If a person has a disability or health condition that was acquired during adulthood, their needs around fertility and assisted human reproduction (AHR) may have changed. Your choice of words, attitude, mode of service delivery, time spent and follow-up services offered will impact - positively and negatively – the disabled person. Cost is a significant factor for disabled people accessing fertility and reproductive services. Where your service does not directly relate to fertility or AHR, consider the impact of any treatment or course of action which you are implementing on this aspect of the person's life, e.g., prescribing medication or therapies which reduce sexual functioning or impact fertility.



'Certainly, sex was never talked about anyways. When I was growing up, in relation to disabled people, we were never considered, even the thought of... I would have friends and they were non-disabled and in teenage years like, everybody had boyfriends. When it came to mine...oh, right – or the assumption is that you wouldn't have a boyfriend and you wouldn't be married, and you wouldn't have children and you wouldn't have an abortion and you wouldn't have all these things. You know, that was not for me and that is still here. That is still around, which is funny.'

– Martina, disabled woman

'Assisted human reproduction is a very complex procedure, it's you know, having IVF is very complex. And it can be very difficult...I suppose again we would see occasionally people with literacy problems and again there's a lot of consent forms and huge amounts of information and I mean, just the, for example, the Children and Family Relationships Act that was recently enacted in May around donor sperm, the consent forms for that are not patient friendly by any shape or means. And for somebody who has literacy problems, or again language problems, they would be incomprehensible. I mean they are incomprehensible at the best of times.'

– Anna, fertility specialist

Do:

- Be sensitive to the fact that reproductive lives are an emotive topic.
- Adapt your communication style to meet the needs of the disabled person.
- Find out in advance if they need any access needs and ensure they are available for their appointment. Where necessary engage translation or interpretation services.
- Use plain English.
- Relay information in a non-biased manner.
- Ensure materials you provide are appropriate and factually accurate. This can involve researching the organisation developing the materials for bias.
- Be upfront about costs involved.
- Consider the impact of your proposed treatment on their fertility and how their disability will interact with the suitability of particular forms of fertility or AHR treatments.

- Allow time for the person to seek other independent advice or to consider information before they make their decision.
- Assume the person has the capacity to make a fertility or AHR decision.
- Share your learning from delivering services in an accessible manner with your colleagues.
- Seek feedback about how the person experienced the service and make improvements.

Don't:

- Assume a disability specific service has or will provide the information being sought by the individual.
- Assume the person cannot afford a particular intervention.
- Assume the person cannot cope or manage with a particular intervention.
- Disclose information about the person to family members/supporters without their express permission.
- Get frustrated if information needs to be repeated or reframed.
- Refuse to provide information about a service on the basis of the person's disability.

2) Accessibility in providing services

Making appointments

When organising appointments for your service, it is important to be aware of the accessibility features of your service. This can include the public transport or parking options to physically attend the service. If someone discloses that they have a disability you should note and follow up on any access needs which they identify. Not everyone making an appointment will be comfortable disclosing a disability but will respond if asked about access needs. Make an offer for a confirmation phone calls texts, letter, or emails closer to the date of the appointment. Be clear at time of booking appointments of what and where the accessible facilities are located. Be as flexible as possible allocating first and last appointments to people who are neurodivergent or have indicated a sensory processing accommodation. Alert staff who will be on duty at that time as to any accessibility requirements. Get in touch with the relevant colleague or department to ensure the accommodation can be provided. Where you are referring the individual for further treatment in another facility or through another service, ensure that those facilities are accessible before organising the referral. Collate information about accessible practical services such as café/restaurant for the disabled person and/or their support member. Give clear directions and provide contact details for if the person needs further instruction while en route. Provide estimated time for the duration of the appointment.

Providing the service

Ensure accessibility accommodation is available in a timely manner and is of a safe and adequate standard. Seek feedback on how the person experienced the reasonable accommodations – what worked well, what didn't - without being defensive or dismissive of their comments. Alert the individual if the accommodation cannot be provided when they are due to attend and make appropriate alternative arrangements without risk to their health or wellbeing. Where the accommodation is the operation of devices or machinery, ensure you are comfortable with their operation. Always ask permission before touching, altering or using the individual's devices – wheelchair, walking stick, hearing aids, glasses, guide dog. Write down the next appointment time

and date in clear language, encourage the person to set a reminder on their phone if it is a more useful for them. Offer to send a letter, email, text or call to confirm the appointment in advance.



'Well, the information, yeah, I had no problem with. The physical access – it wasn't too bad, but now they wouldn't have had the proper lowering couches or hoists or anything like that. We could just about manage, and I was a little bit fitter than I am now, but I believe since then...I remember watching a TV show about the Sims Clinic there about a year or two ago, and they've totally rebuilt, it's a really modern facility, so I'd expect it's much more accessible now. But the important thing, their attitude was accessible and that really made all the difference like.'

– Martina, disabled woman

'One of my earliest memories as a professional coming into contact with somebody in a wheelchair was when I worked in another family planning clinic many, many years ago. And we had a man in a wheelchair arrive up. I was completely inexperienced in terms of dealing with somebody with a disability like this in the professional capacity. So, he arrived up in a taxi and the taxi had the little ramp thing that he came out of and there were steps into the clinic that I worked in... And I backed the wheelchair up the steps, and he kept saying, 'No, no, hang on.' And I said, 'No, no, it's fine'... The wheelchair fell on top of me and then it was a huge palaver, and I was mortified because first of all I was hurt, and secondly, I was mortified, and thirdly I just felt so bad that I had been so stupid and caused this poor man such distress. And he was sort of...He came into the clinic with his hand like this over his face.'

–Anna, Fertility specialist

Do:

- Make it standard practice to ask everyone if they have any support needs. Be able to advise on the access features of your service.
- Ensure the relevant staff or colleague is alerted to the person's access needs in advance of their appointment.
- Make sure ancillary staff – car park attendants, catering, porters, reception staff – are knowledgeable about and ready to provide for access needs.
- Be creative in problem solving. Learn from Disabled People's Organisations and Non-Governmental Organisations about potential options and support networks.
- Adopt the language the individual uses, name first.
- Ensure that access needs are communicated to relevant staff in advance of any follow up appointments, internal or external to your own service.
- Ensure that any services the person is referred to are accessible.

Don't:

- Attempt to source the accommodation when the individual arrives unless you are certain it will be appropriate and available.
- Accept that your service cannot be made accessible due to lack of knowledge or finances.
- Speak to the person's supporter rather than the person themselves about their issue.
- Decline to provide a service due to a person's identified needs.
- Assume that everyone with the same impairment type needs the same accommodations.
- Assume that the person's access needs will not change, depending on the impairment type.
- Treat the person as difficult or problematic either directly to them or within your professional networks.

3) Decision making support and ensuring informed consent

Disability advocates have been vocal about the impact of involuntary or non-consensual interventions over their bodies and lives. Because fertility and Assisted Human Reproduction needs are such an intimate part of our lives, it is imperative that all necessary information is provided in an accessible format. The manner of relaying that information must be respectful and appropriate to the situation. As with the non-disabled population, disabled people may rely on the experiences of others to assist them in their decision making while retaining the power of making the decision for themselves. For all approaches to securing informed consent, everyone enjoys the presumption of legal capacity. That means that they should be supported to make their decisions and that it should be respected and adhered to where possible.



“I suppose why I came was, how I made a decision that really kind of bothered me for a long time was when I was in my early twenties, I remember one day kind of making a clear decision of not to have any children, because I decided, the condition of my impairment, it would deteriorate and it is deteriorating. And my fear was that somebody else would be either rearing my child, because I wouldn’t be seen fit to do it, or if I had a personal assistant, they would be lifting my child.”

– Jean, disabled woman

“So, I had like a two-week window before I started into my cancer treatment and that, I couldn’t get to speak with my oncologist about it at the time. It was like as if they just didn’t think that was important or to talk to them about it. So, I was left kind of with all these decisions. So, I had this support in Dublin, which I sought after, went to see, got their advice, but I couldn’t get the second part where I needed to talk to my consultants about what the way forward was.”

– Sue, disabled woman

“I still think then you have this protective thing and it was interesting, the “protected person” came in which is just another word for somebody who can’t consent, you know. I just was like oh for God’s sake, here we go again... [Law makers] are scared of people with disability reproducing. So, we want to put in only if they consent and more, they need to know more than the average person to prove that they can consent so that annoys me a lot I have to say.”

– Anna, fertility specialist

Do:

- Support the individual to consider all the options available to them.
- Where possible speak to the person individually or with independent interpreter/supporters.
- Promote peer support for exchange of experiences about particular options.
- Make use of communication tools which the person has indicated they are comfortable using.
- Allow plenty of time for discussion and decision making.
- Depending on the nature of the treatment, reassure the person that a decision can be revisited at another time, or an alternative option is available if their initial choice is not suited to their needs.
- Consider the impact of any fertility treatment on the person’s health and wellbeing or future fertility.

- Consider the potential impact of proposed medical treatments on the person’s fertility and contraception and advise appropriately.
- Allow time and space for change of mind about consent to a treatment, or to adapt the treatment.
- Use a ‘will and preference’ based approach to ascertaining the person’s wishes on the matter.

Don’t:

- Assume that an existing treatment has been consented to and can be continued without getting informed consent.
- Assume that information relayed to a family member or support person is being communicated accurately or without bias to the individual.
- Allow a support person or family member to make a decision about the person’s fertility or contraceptive treatment.
- Deny someone the opportunity to take a risk or make a decision which you personally would not make.
- Point the person towards biased information with a particular religious/political ethos.
- Trigger an assessment of legal capacity process in relation to a fertility or AHR decisions.

4) Addressing objections to accessing fertility and AHR services

Services should ensure that the will and preferences of the person regarding their fertility and AHR choices are respected. You should recognize that disabled people are often reliant on supporters to access information or to be assisted in understanding information. While supporters may be well-meaning, they may also layer the information with their own biases and opinions to persuade the individual’s choice. Furthermore, professionals can also project ableist attitudes to their provision of services which they would not do to non-disabled clients or patients. Access to fertility and AHR services should not be restricted because of service providers objections on any disability-related grounds. This is relevant at both disability support service level and medical provider’s level.



And now, while I was in [a fertility specialist] room, he went to great pains to tell us about all the disabled women he had helped, but they had all had an acquired impairment through diving accidents, or what have you. None of them were genetically disabled people. Which was, you know, it was quite clear what he was saying basically – he didn’t want to take the risk of being responsible for another disabled child coming into the world, even though that wasn’t an issue for myself or my husband.

– Elaine, disabled woman

‘I find the thing that you come up against often is, sorry I’m going off on a tangent now, is not the [disabled people] themselves, it’s often parents and parents see our guys as children often and you find that that’s what you’re coming up against and it’s trying to educate parents in saying, ‘Well you know this is age appropriate material we’re giving them in terms of children and then trying to see when they’re adults that they have the same rights as anybody else and should be allowed and encouraged to explore their sexuality’ but often that’s a huge thing that you come up against, is parents.’

– Mark, Intellectual Disability Support worker

Do:

- Assume the person has capacity to make decisions and to access services.
- Support the individual to consider all the options available to them.

- Speak with the person separately from anyone accompanying them to ascertain their will and preferences individually.
- Provide unbiased, evidence-based information.
- Remind families that where the person is over 18 years old and is not under any court order or wardship that they cannot make decisions on the disabled person's behalf.

Don't:

- Put policies in place which require support people or family members to take responsibility for giving/denying consent for treatments.
- Liaise with anyone other than the person receiving the service without their consent.
- Provide biased information.
- Assume that an individual is not a candidate for your service or treatment based on their impairment.
- Ignore ableist comments or actions by colleagues. Revert back to your organisation's code of conduct which should include principles of equality and non-discrimination.

5) Accessing consultations in private/specialist services

While regulation for AHR services is being developed, nothing prevents private actors from providing their treatments and services in a manner which respects the rights of disabled people on an equal basis with others. It is important to recognize that an individual's fertility can be an emotive topic regardless of - or because of - other issues in their lives such as disability or a medical diagnosis. Respond to disabled people's queries without judgement. When discussing complex medical interventions for the person's fertility preferences, ensure that they are aware of all aspects of the treatment. Use clear information about cost, timeframe, appointments and follow-up requirements. Discuss the pros and cons of each option with adequate time for questions and consideration.



'So the next day actually I had an appointment with a quite renowned Irish neurologist. Again, a first appointment. I went into the room. The first thing she said to me was 'What are you doing here? I'm not supposed to see you for another six weeks in a different hospital.' I said 'Okay.' That was a bit of a shock. Then I told her about (consultant) and I showed her the handwritten letter he'd given me of questions, and she just skimmed down them and looked at me and went 'Oh no, no, no. You could never have a child. You'd never get past 20 weeks' and handed me the thing back and sent me on my way... like she did that to me, but we fought back in other ways, and we got where we needed to be, but I often ask myself 'How many lives has she ruined through her prejudice and her insensitivity.' That really, really annoys me about her. But so that was quite a wrench, and it took us a number of years to recover from that really.'

– Kaye, disabled woman



'But a huge demographic within users of assisted human reproduction... they have some issue with their uterus, or they've had cancer and they've saved their eggs but had a hysterectomy or something like that.... And there is a very little understood relationship between mental health and infertility.... So this is kind of speculative but I think there are mental health sides to that story. And obviously the fact that assisted reproduction is totally unregulated in Ireland. There is no protection for anyone. You're totally dependent on the internal ethical decisions of private fertility clinics.'

–Maebh, Barrister

Do

- Incorporate a human rights and equality ethos in your services.
- Give non-judgmental information on all available options.
- Provide information in accessible and understandable formats.
- Where equivalent services are more affordable or more available in other jurisdictions signpost the person to look into those options.
- Consider the potential impact of proposed medical treatments on the person's fertility and advise appropriately.

Don't

- Assume that an existing treatment has been consented to and can be continued without re-establishing informed consent.
- Assume that because there is a disability or particular socio-economic circumstances that the person does not have an interest and desire to preserve or control their fertility.
- Proceed with a form of fertility treatment because of perceptions of convenience.
- Prevent a person from accessing a fertility service because of conscientious objection by yourself, family member or support person or organisation.

Case Study: John

John is a newly married man in his late 30's who has cerebral palsy. John and his wife wish to have children as soon as possible. They have had preliminary contact with a private fertility clinic. After disclosing John's diagnosis their fertility specialist said she wishes to consult her colleagues as there is a potential ethical issue with providing treatment in light of this new diagnosis. At the appointment, the doctor casually says, 'Do you not have enough to be dealing with without adding the stress of a baby?' The fertility clinic request assessments from John's medical team about the impact of the disease over the next 20 years. They quiz John's wife about how she will cope minding a child and a dependent partner. Their financial security and family support systems are questioned. This has added extreme stress and worry to the couple.

How could this service have been better delivered to John? Consider:

- Discriminatory delay to providing the treatment based on John's disability.
- Bias about his ability to parent.
- Intrusion into other areas of John and his wife's lives.
- Offensive remarks made about John's decision to become a parent.

B. Contraception and Sterilisation

Disabled people's experiences of contraception and sterilisation can be contrary to that of the general public. Perceptions by family members and disability service staff can dictate attitudes about whether an individual should be sexually active or become a parent and this can lead to excessive intervention in disabled people's access to contraception and sterilisation. Protectionist and sexist attitudes can lead to the denial or the enforcement of either contraception or sterilisation without the full informed consent of the individual.

Top Tips

1) Information provision about contraception and sterilisations

Information is central to enabling decision making on this area of disabled people's lives. There has been some progress on relationship and sexuality education from primary school onwards but many of the current disabled adult population have not had the benefit of RSE. If your work engages disabled people on the provision of contraception or sterilisation, ensure that materials and mode of delivery are accessible to your audience. Ask the person or group that you will be working with about their communication needs well in advance. Liaise with Disabled People's Organisations (DPOs) to find or devise accessible material. This might involve providing sign language interpretation, Easy-to-Read documents or Brille. Accessible, screen-reader compatible, plain English literature should be provided as standard. Consider whether group work is appropriate, allow frequent breaks for concentration and put in place follow up activities to make sure information is revised if necessary. The forthcoming free contraception scheme for 17 to 25-year-olds is welcome and practitioners should put all measures in place to ensure eligible disabled people are informed and have access to the scheme on an equal basis with others.



[Speaking in relation to cancer treatment and fertility information] *'I had a, I actually had a Breast Care Nurse, but she didn't provide any information or support on it either and I found out by default by ringing the fertility clinic in [town] that there was a programme in the Rotunda for cancer patients that actually, for young cancer patients to preserve their fertility, and it's a fully government funded programme.'*

– Sue, disabled woman

'Yeah, we would have like most of the time we would use sex education material that is geared for a younger age. Do you know like, I don't think there is enough for different levels of disability? I always had a bee in my bonnet about that, especially learning disabilities, is not just functioning at a younger age, it is a different way of thinking.'

– Max, psychologist in social work agency

Do:

- Ask what specific information the person is seeking.
- Find out how the person communicates and what format the information you are relaying should be provided.
- Link in with DPOs and advocacy groups for materials to share.
- With the person's permission, link in with their support network to assist their understanding of information provided.
- Consider their other identities such as LGBTQI membership and ethnic minority status to tailor the information to their needs.

Don't:

- Assume that disabled people do not need contraception education and information, regardless of the nature or origin of their disability.
- Assume that they have already received appropriate information earlier in their lives or from other sources, such as a disability service.
- Disclose to family, friend or disability service staff member that the person is seeking this information without their consent to do so.
- Do not assume that the law prevents you from providing information to adults with intellectual disabilities.
- Do not allow a support person or family member to make a decision about the person's fertility or contraceptive treatment.

2) Recognising the right to contraception and sterilization services

Will and preference of the person regarding their contraceptive choice must be the primary factor. Sterilisation solely due to menstruation management or behaviour control violates the rights of the individual where there is coercion to receive the treatment. Disabled people have a right to access healthcare and make decisions about becoming a parent, not becoming a parent and their body on an equal basis with non-disabled people. Families' and supporters' fears of pregnancy - through either consensual sex or assault - do not justify the violation of the disabled person's right to bodily autonomy and to reproductive justice. The person must be informed about any treatment or service they are availing of and any long-term consequences of that treatment to their health or future fertility.



*I was in hospital, and I think I had pneumonia and like I, I'm on the pill and the nurse was kind of saying 'Well you don't need to be taking that sure...' you know, because I think they were worried about a clot and there was no clot but and I knew there was no clot, but they were worried. But anyway and she went 'No, just you don't need to be taking that and...' and I said to her 'But there is, I don't want to, I don't want to get my period' kind of thing and it was just... it was just the way she was saying it was kind of...
Interviewer: Did she feel you weren't sexually active?*

S: And yet she knew I was married?... And I just thought that was strange you know?

– Jen, disabled woman

'Um, we work with the, mostly with the Rotunda hospital fertility. It used to be the Herring unit; it's now IVF Ireland I think it's called. When we started going there, 30 odd years ago, there was no access. you were seen in a corridor. But they have got wheelchair access there. The difficulty I suppose is that for some of the procedures, for testicular aspiration or biopsy, they won't do it there for our patients because they would need to be hoisted or transferred over on to a, the table or whatever you want to call it. So that creates a difficulty then as well of trying to have the procedures done within the fertility clinic. Now some others, I'm not sure around the country how accessible they are. But certainly, it's a difficulty we've had on occasion with the one we're working with mostly.'

– Anne, fertility specialist

Do:

- Consider whether your services are accessible to disabled service users in terms of attitude, information and physical barriers.

- Make adaptations to enable the person to use your services.
- Upskill or engage in continuous professional development to ensure you are confident to deliver your service to everyone in the community.
- Recognise that disabled people have other identities, including as members of the LGBTQI+ community and may have contraceptive needs outside of the heteronormative framework of sexual health services delivered currently.
- Respect decisions of the person to proceed with a treatment where they have been given appropriate information and have indicated informed consent.

Don't:

- Assume disabled people do not have sex lives, or that they are exclusively heterosexual.
- Have policies in place which discriminate on the basis of disability.
- Escalate a social welfare concern for hypothetical/unborn children on the basis of the parent's disability.
- Perform treatments without full and informed consent of the individual.
- Don't agree to treatments which are being requested by family or service staff for convenience - e.g., sterilisation for menstruation management or Long-Acting Reversible Contraception without consent of the individual due to fear of pregnancy.

3) Addressing the influence of family and supporters on access

Services should ensure that the will and preferences of the person regarding their reproductive lives are respected and access to appropriate services is facilitated. You should recognise that disabled people often have their voices silenced or opinions influenced by their family and supporters due to lack of access to alternative information or reliance on their support means the person cannot safely or comfortably reject or disagree with the attitudes of their supporters. Furthermore, professionals can also project ableist attitudes to their provision of services which they would not do to non-disabled clients or patients. Access to contraceptive and sterilisation services should not be restricted because of the practitioner's objection on any grounds. This is relevant at both disability support service level and medical provider's level.



'People when I told my social worker at the time that I wanted to have kids, she was like, 'No, you're not going to have kids, you're not going to be able to have kids, I'll contact TUSLA and all to let them know you're disabled and all that', I was like, 'Go ahead and contact them, I've nothing to hide, like yeah just because I'm disabled doesn't mean that like I can't parent my child' and stuff like that so I had people put me down you know like saying, 'Oh no you can't do this, you can't do that', and I'm like, 'Who can't?' I'm like, 'If you're well able to do it then I'm well able to do it, it just takes me a bit longer to do it but'.

– Jen, disabled woman



'I had a call from a women's hospital...They explained that they weren't sure whether this individual could actually consent to the procedure that was being recommended. And the ethics board had asked for a capacity assessment. So, I asked what had they done so far to actually help the person understand the procedure and to give informed consent based on the understanding. And they said they had given them the leaflet that they have in the hospital on the procedure. They then realized that the person couldn't read... I think sometimes the disability overshadows common sense. This perception of oh there's a disability, we don't know what to do, lets refer to the ethics board. Instead

of saying, what is our actual question here. What are we trying to assist this person in understanding and what do we need to make sure it is informed consent.'

– Jane, psychologist in an intellectual disability service

Do:

- Make clear to family members, support workers and disability service organisations that they do not have a right to make decisions relating to contraception and sterilization for another person.
- Support the individual to consider all the options available to them.
- Where possible speak with the person separately from anyone accompanying them to ascertain their will and preferences individually.
- Familiarise yourself with their communication style to be able to speak directly to them.

Don't:

- Put policies in place which require support people or family members to take responsibility for rise/give consent for treatments.
- Liaise with anyone other than the person receiving the service without their consent.
- Provide biased information.

4) Accessing mainstream services – chemist, shops, GP, Family Planning services

With the exception of rehabilitation related services, there are no disability specific fertility and contraception services in Ireland. Existing mainstream services must be accessible to everyone in an equal manner. Contraception in particular is available widely in the community varying from supermarkets and vending machines to GPs and chemists. Staff within all these settings have a role in ensuring equal access to contraception. With the announcement of free contraception for 17–25-year-olds, the relevant providers must ensure their services are accessible to ensure equal provision for disabled young people.



'[The doctor said], 'Well, normally, after four months we actually examine you.' I said, 'Why would you do that?' He said they just wanted to make sure there was no bumps and stuff like that. I said, 'Right...' Then he said, 'We don't need to do it with you.' And I went outside, and I went home, and I thought - yes, you do, you do need to do that with me. So, now I am in the process – I wrote a letter to them objecting to the treatment that I had been getting and being treated differently from anybody else. So, I am waiting from a response from them on that. I just kind of felt - you haven't got a fucking clue. I thought you don't have a fucking clue how to treat me.'

– Jen, disabled woman

'So it was agreed that somebody would work with [a man with an intellectual disability], who he could contact, how he could talk to his GP, how his GP could make a referral, etc. to one of the hospitals in Dublin for genetic counselling and genetic assessment. And that was done. And he was told that as he wasn't in a relationship and as he wasn't sexually active that this service wasn't going to be made available to him....but I suppose we would query and did query and we still haven't got this resolved around whether this can actually be made available to him. and was the intellectual disability the discriminatory factor, we don't know.'

– Jane, psychologist, Intellectual Disability Service

Do:

- Provide your service on an equal basis with other customers/clients/service users.
- Make your service accessible in terms of physical, information and attitudinal accessibility.
- With the person's permission, link in with their support network to facilitate a treatment (e.g., contraceptive prescription) or purchase (e.g., condoms) be fulfilled.
- Check that the person is comfortable using/administering the treatment. Dexterity and comfort with consistently taking tablets could influence this.
- Ensure the indicated accessibility measures are available when necessary.

Don't:

- Require permission from a non-disabled family member or support person to purchase/fill the prescription.
- Inform a support person about the person's receipt of service without their permission.
- Assume specialist knowledge or skills are required to deliver the service.
- Provide a sub-standard of care to a disabled person because it is difficult to facilitate their access to the full standard of care.

5) Decision making support and informed consent

Disability advocates have been vocal about the impact of involuntary or non-consensual interventions over their bodies and lives. Because our fertility and contraception needs are such an intimate part of our lives it is imperative that all necessary information is provided in an accessible form and the manner of relaying that information is respectful and appropriate to the situation. As with the non-disabled population, disabled people may rely on the experiences of others to assist them in their decision making while maintaining the power of making the decision for themselves.



'My sister had spoken to me and said would you consider sterilisation. ...And so, I was unsure.... She said, because you're pregnant, pregnant, pregnant. So, I spoke to my husband about it, my husband was like, no, no. He said, I can't stand it, no. I was thinking, well I don't know. But at the same time, we didn't know, we didn't have the information, so how could we have a conversation about it? Two weeks prior to the labour, my sister said to me, come with me, let's talk to the doctor about sterilisation. I said, okay. I said, do you want it... I just followed her, and I just said, yes, I complied. ...The doctor made sure that I wanted a sterilisation, and I, still unsure, and I just went, okay. And my sister was there at the time, so that conversation was going on. So, I was fitted in, they said, okay, get ready, signed a form. That evening, a doctor and a woman came, did a physical check, to be ready for the next morning. There was that communication thing again.'

– Sinead, Deaf woman

'[One case] was where a brother, the mother and father were dead, the brother again was more than happy for his brother to be with his girlfriend and live in the house. But he was saying that I'm not taking on another child at this point in time. So, they got 'consent' [for the brother with an intellectual disability] to be sterilised. And a number of sterilisations in males would have been along that sort of continuum really. And it was much easier at that stage to get the... Well, easy is not quite the word but it was easier for males to be sterilised than females.'

– Jane, psychologist, intellectual disability service

Do:

- Support the individual to consider all the options available to them.
- Where possible speak to the person individually or with independent interpreter/supporters.
- Promote peer support for exchange of experiences about particular options.
- Make use of communication tools which the person has indicated they are comfortable using.
- Allow plenty of time for discussion and decision making.
- Depending on the nature of the treatment, reassure the person that a decision can be revisited at another time, or an alternative option is available if their initial choice is not suited to their needs.
- Consider the impact of any fertility and contraceptive treatment on the person's health and wellbeing or future fertility.
- Consider the potential impact of proposed medical treatments on the person's fertility and contraception and advise appropriately.
- Allow time and space for change of mind about consent to a treatment, or to adapt the treatment.

Don't:

- Assume that an existing treatment has been consented to and can be continued without getting ongoing informed consent.
- Do not assume that information relayed to a family member/support person is being communicated accurately or without bias to the individual.
- Do not allow a support person or family member to make a decision about the person's fertility or contraceptive treatment.
- Consider the impact of any fertility and contraceptive treatment on the person's health and wellbeing or future fertility.
- Consider the potential impact of proposed medical treatments on the person's fertility and contraception and advise appropriately
- Provide or point the person towards biased information with a particular religious/political ethos.
- Trigger an assessment or denial of legal capacity process in relation to a fertility/contraception decision without exhausting all possible mechanisms. Use a 'will and preference' based approach to ascertaining the person's wishes on the matter.

6) Delivery of service

Attitude and actions towards the person can have a lasting impression – for good and for bad. Recognise that the person has a right to the same standard of care as all service users and has likely encountered many obstacles to reach this point of receiving the service, whether it is difficulty accessing information, physically presenting for the service or discriminatory attitudes from previous professionals. Disabled people are the experts on their own lives, however having to recount their needs repetitively or justify why they want to proceed with a contraceptive or sterilization service is burdensome on the person.



'You know that I just think it's and again, I would be against forced sterilisation you know, people with different disabilities getting sterilised, against their will but I think it's the same as a woman should have the right to choose if...

Interviewer: You're requesting and you're consenting, you know.

And like you're going, 'I know the facts, I know I'll never be able to do this, this is not what I want, I don't want this, I don't want to have children that they don't seem to

understand. You know, it was, I don't even know again if they saw the disability, you know or if it's just 'women should not be getting sterilised.' The doctor said to me, the first thing, 'You have no right to choose whether or not a child is born.'

– Kelly, visually impaired woman



'So, we've moved from being haphazard all over the hospital, sometimes up steps, to three assessment rooms on a ground floor which are wheelchair accessible. They might not be the most seamlessly accessible, we have no toilets on site but we're having to traipse across campus for toilets but that's all of us. I think it would be good to work with the NGO support people who are deaf and blind to see what we could do to enhance our interaction with members of the deaf and blind community.... It's part of the difficulties of being housed in a 17th century building.'

– Pat, perinatal psychiatrist

Do:

- Read any information on file about the person's previously identified communication or access preferences.
- When an appointment for consultation or treatment is being made enquire whether the person has accessibility or support needs. Arrange for these needs to be met in advance of the person presenting at the appointment. For example, booking a physically accessible room or sign language interpreters.
- Where more than one appointment is required in one day – a pregnancy test/blood test/insertion of contraceptive device, where possible schedule them in physically close locations or allow adequate time to travel between locations.
- Where there is an Access Officer use their knowledge to meet the accessibility needs of the person.
- Highlight concerns and solutions around accessibility to the appropriate colleagues/departments for resolution.

Don't:

- Deny a contraceptive or sterilization service based on disability or your perceptions of who should be availing of your services.
- Ignore inaccessible facilities or services.
- Don't expect the individual to know how to navigate inaccessible spaces.
- Don't rationalise inaccessible facilities due to low levels of demand.

7) Follow up consultation

Disabled people often need to undergo trials of different forms of treatment to find the one most suitable to their lifestyle or comfort level. The person should know what to expect in the aftermath of the service or treatment and be able to make contact with you or a member of your team who can respond to their queries or if they need further or different interventions. It is important to recognise that the person may have work or caring commitments or other reasons why making a return visit may be challenging. This can be particularly difficult for disabled people who have limited access to transport, are experiencing domestic violence, are in the Direct Provision system or for whom English is not their first language.



‘Interviewer: And how did you feel afterwards, once you were sterilised, is that...?’

Jen: I had no feeling on it, I just carried on.

Interviewer: When you look back now, would you have chosen a different procedure or a different form of long-term contraception, perhaps?

Jen: I think so, yes – I think so. That contraception and knowing what they were. With [the disabled women’s support group], they have talked about other forms of contraception. [I was] a little bit gob smacked to see those kinds of stories, and it was this thing in your head of going, oh I should have, yeah, I should have.’

– Jen, disabled woman



‘I’ve had clients who had absolutely no vision, blind. A couple who wanted to have fertility treatment in order to conceive. And I struggled with the notion that this couple were going to have treatment, have a baby, and then care for that baby with no sight...So, I did an implications counselling session. That was my role. And that was to talk about fertility treatment, what to expect, how you can prepare yourself, what sort of supports you need to have in place. The only difference with that couple was they

lived independently and their lives were managed really, really well. And then we just needed to talk about what supports they’d need to put in place if they had a pregnancy and had a baby and were minding that baby. And that wasn’t me sort of assessing to see will you be OK to have... You know, are you OK to have a baby? This was like, OK, this is going to happen. If it does happen, what supports would you need to put in place? So, they had really good family and friend support.’

– Laura, fertility specialist

Do:

- Consider ways for the person to give feedback about their experience of the service.
- Give clear information about what to expect in the aftermath of the treatment.
- Provide accessible information and support them to make an informed decision.
- Reflect on your experience of providing the service to a disabled person. Consider any gaps in your knowledge and how to improve the delivery of your service.

Don’t:

- Assume the initial treatment or service was satisfactory or successful.
- Make people feel guilty or burdensome for requiring follow up care.
- Liaise with a family member or support person without the individual’s consent.
- Assume that because one treatment or intervention was not appropriate or successful, that no others will be based on the person’s disability.

Case Study: Tina

Tina, 25, is a woman with an intellectual disability. She receives support in her home from a disability service. She resides with 3 other women aged between 20 and 40. Tina has never expressed that she has had sexual relations. She attends a day service which is a mixture of people, men and women, from age 18 to 65. Tina’s mother removed her from classes which discussed sex education during secondary school. A letter came for Tina inviting her to attend a Cervical Check appointment. This prompted a support person to enquire about Tina’s sexual history and she asked Tina’s mother whether the service can organise for the contraceptive implant to be administered, just to be safe. Tina’s mother has said she does not give consent for either the Cervical Check appointment or the contraception as she does not believe Tina to be sexually active. Tina’s mum indicates that if actions were going to be taken, she would prefer a hysterectomy to be undertaken to guarantee Tina won’t have children after the mother is no longer able to care for them.

How are Tina’s reproductive rights being impacted here?

Resources

Resources for fertility, contraception, pregnancy and loss

- WellWoman Centre: <https://wellwomancentre.ie> .
- Irish Family Planning Association: <https://www.ifpa.ie> .
- National Rehabilitation Hospital Sexual Wellbeing Service: <https://www.nrh.ie/about-nrh/nrh-statement-purpose/departments/sexual-wellbeing-service/>.
- A good general guide for going to the doctor is 'Doctors and Us – What it is like for people with learning disabilities to go to the doctor in Ireland' by the Inclusive Research Network: <http://www.fedvol.ie/fileupload/Inclusive%20Research%20Network/IRN%20Doctors%20and%20Us%20Report%20Final.pdf>.
- Easy Read information on contraception from Devon Sexual Health: <http://shorturl.at/ioxU8>.
- 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>.
- Association for Improvement of Maternity Services Ireland (AIMS): <http://aimsireland.ie> .
- 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>.
- Leanbh Mo Chroí is a peer support network for those who have been told that their baby will not survive when it is born: <https://lmcsupport.ie>.
- Citizens Information: Fertility treatments and assisted human reproduction in Ireland: https://www.citizensinformation.ie/en/birth_family_relationships/before_your_baby_is_born/fertility_treatments_and_dahr.html
- Enhance the UK provides information related to sex, relationships and disability: <https://enhancetheuk.org/>.
- Patient.info: Guide to communicating with persons with intellectual/learning disabilities from UK, See 'Communication section of ', General Learning Disability,' <https://patient.info/doctor/general-learning-disability#ref-1>
- University of Limerick Engage: Plain English legal explanation of Donor Assisted Human Reproduction: Community Briefing, Information booklet on Donor Assisted Human Reproduction (DAHR) and the Law in Ireland, <https://www.ul.ie/engage/sites/default/files/2017,%20No%2013%20Information%20booklet%20on%20Donor%20Assisted%20Human%20Reproduction%20DAHR%20and%20the%20Law%20in%20Ireland.pdf>
- HSE (Health Service Executive). Quality and Safety Patient Directorate: Consent a guide for health and social care professionals. <https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/guidehealthsocialcareprof.pdf>
- Medical Protection Society, Consent to medical treatment in Ireland, 2015. <https://www.medicalprotection.org/docs/default-source/pdfs/Booklet-PDFs/ireland-booklets/consent-to-medical-treatment-in-ireland---an-mps-guide-for-clinicians.pdf?sfvrsn=0>
- Breast Cancer Care: Fertility toolkit for healthcare professionals. https://breastcancernow.org/sites/default/files/files/bcc228_fertility_toolkit_hcp_2017.pdf



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