

Re(al)
Productive
Justice

GENDER AND DISABILITY

Communication Guide

for
Health and Social Care Professionals



OLLSCOIL NA GAILLIMHÉ
UNIVERSITY OF GALWAY

CENTRE *for* DISABILITY
LAW & POLICY

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About the Communication guide

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 listened to and properly supported in those choices. However, many barriers exist which prevent disabled people from having the same choices as everyone else. This guide focuses on how practitioners can break down barriers by attending to accessibility requests and respecting the different ways in which disabled people may communicate their needs and preferences.

Who is this guide for?

The purpose of this guide is to assist professionals in their supportive role as they engage with disabled people to ensure their rights are respected. The way in which requests for support are listened to, acknowledged, and acted upon can make the difference to both the process of support and the resulting outcome. From our research, we have heard from professionals how limited resources stymie the way in which they would like to support people. However, people with lived experience of disability speak of the ways in which accessibility and provision of support by professionals can be improved with some important changes. This guide aims to equip professionals with a broad range of approaches to successfully support people with disabilities at initial stages and their corresponding referral avenues, ensuring that from the outset their lived experience is acknowledged respectfully. It is crucial that all avenues in the provision of support and decision-making consider the accessibility requirements and will and preferences of the person requesting the support.

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 guide 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. We also recognise people who identify as disabled or as having a disability. The reproductive justice framework includes not only the right to not have a child, but also the right to have children and to raise them with dignity in safe, healthy, and supportive environments. It looks to the broader social, legal and institutional structures in which people make reproductive decisions. The intersection of disability with reproductive justice enables us to consider the specific barriers disabled people encounter in relation to reproductive decision-making and care.

What topics are covered in this toolkit?

This guide focuses on accessibility, communication and provision of support to disabled people by professionals working in the area of reproductive health.

Who made this toolkit?

The guide was developed by researchers at the Centre for Disability Law and Policy, University of Galway, as part of the Re(al) Productive Justice: Gender and Disability project. We benefited from collaboration with our stakeholder and ambassador group which includes a range of disabled people and health, social care and legal professionals whose work includes reproductive rights in law, social work and the health sectors. The project has developed toolkits for professionals to use to improve how they deliver their services to disabled people. We also want disabled people to know the rights they have and the standards they can expect when receiving services and support about making decisions to have - or not to have - children.

Where can I go to 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 Know Your Rights 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.

Communication Guide

Those who provide public services are obliged by law to ensure that services are accessible to disabled people. A number of laws and policies relate to accessibility and the rights of disabled people around information and communication in Ireland:

- Right to equality (Irish Constitution, Article 40.1)
- Right to non-discrimination (Equal Status Acts)
- Right to accessible public buildings (Disability Act 2005 and Part M of building regulations)
- Right to assessment of need (Disability Act 2005)
- Right to reasonable accommodations (Disability Act 2005 and Section 42 Irish Human Rights and Equality Commission Act 2014)
- Right to Irish Sign Language Interpretation from public bodies (Irish Sign Language Act 2017)
- Right to have decisions legally respected (Assisted Decision Making (Capacity) Act 2015).

Some elements of accessibility relate to the inception and design of services and facilities; however, there are many ways for providers to make their services accessible to disabled people that require low investment or are cost neutral. Accessible, considered communications processes and the provision of information in formats adapted to the needs of the individual disabled person are at the core of equitable access to care and support. All staff should be aware of the accessibility features of their service and be equipped to meet the communication needs of disabled people when they interact with them. Knowledge and resources can offset the awkwardness some staff may feel when asking about accessibility and communication needs. This guide will provide some examples of simple ways that practice can be changed in order to improve the experiences of disabled people who access your services.

1. Staged process of communication

Making appointments

When the person is making appointments for support 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. See this 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 people with assistance dogs. People 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 D/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.

To assess the accessibility of your service you can glance through the basic checklist of questions below to assess the current level of accessibility of your appointment-making service and identify any gaps:

- Does your appointment process or service describe the physical environment of the location in which the service is provided?
- Does your service an option for a person to respond with any physical access needs they may have to navigate that space.
- When a person is making an appointment for your service is there a question about Information access needs e.g., ISL interpretation, plain language, braille or other.
- Do you ask a general question as to whether there are any other access needs that you can support? This covers examples where someone does not identify with having a disability but does have specific access needs.
- Do you ask what format the person would like to receive any further communication or follow-up information by your service?
- If you have asked what accommodations the person needs before they arrive, do you listen and respect the person and not make assumptions?

Such audits of aspects of your service are easier done if the perspective of disabled people are included. It is possible to hire accessibility consultants, although engaging with and getting feedback from existing disabled patients or clients may be sufficient to identify accessibility gaps.

Accessible service provision

If you provide a public service then part of the public service duty is to provide an access officer. This can often be the first port of call. If you are service that supports disabled people there are many ways in which your services can be more accessible for them. 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 you find someone's access request unusual or 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, but work as best you can to provide that 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 stated. For example, depending on the individual's condition, they may walk unaided or using crutches on some days but use a wheelchair 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 so it should continue to be provided unless the person says they no longer need it.



Exercise

You can complete an access audit of your services. This means that you can structurally look at what you are offering and the way in which it is accessible to a broad range of disabilities. To do this, you can get someone from DPO's (Disabled People's Organisations are run and controlled by disabled people – these are different from Disability Service Providers) to do an access audit from different disability perspectives. You can talk to staff about embedding accessibility within staff training. It is important that anyone who will be a first point of contact has accessibility training.

Providing information in accessible ways

In the “Making appointments” section we saw how when someone discloses a disability you can provide information on the type of accessible service provision possible and discuss the ways in which this can be adapted to suit their needs. Prior to their appointment, it may also be possible to ascertain whether they require information in an accessible format. For instance, a leaflet with information will not effectively communicate with someone who is visually impaired or blind. Instead, it is important to ask them how they consume information. For instance:

- Do they read Braille or use a screen reader?
- If so, what type of documentation does their screen reader support?
- Does the person respond better to visual images and plain language or easy-to-read format?

If the person is D/deaf it is essential to book ISL interpretation and to ensure that an interpreter is booked for all meetings the person may require. It is important to consider the way in which you intend to communicate the information to the person so that it can be understood, and an informed decision can be made. If the majority of information about your service is not available in accessible formats it is worth employing an organisation like Inclusion Ireland to collaborate and transform your information into easy-to-read format: (<https://inclusionireland.ie/wp-content/uploads/2020/10/makeiteasyguide2011.pdf>).

2. Researching referral options based on the person's wishes

New connections or referrals may be required based on the specific access needs and the specific request of support that the person has asked for. This could mean that you may have to call a service, agency, or organisation that you have, or have not, engaged with before but that can provide or adapt its service provision to adequately support the person in the way they have expressed. If a particular service is not available then it is important to provide various options for the person to consider what they think will suit them best from the options available.

If you are providing a referral, it is important to assess whether the referral service is accessible for the person in question. It is also helpful to ask the person whether they would like their access requests transferred when the referral is being made. If they consent, this ensures that the person does not have to repetitively provide information on their access needs as they engage with other services that they have been referred to.

Scenario: Kate

Kate is pregnant with her first child. She also has a physical disability that means she needs to learn specific techniques to hold, feed and change her child and as it develops and grows.

What type of referral can you make to support her in learning these techniques?

Suggestions: Peer support groups or DPOs; Physiotherapist; Occupational therapist

Kate is also thinking ahead about baby equipment and what type of equipment is accessible for her. What do you recommend? (See this example from Northern Ireland of equipment for parents with disabilities: <https://www.nidirect.gov.uk/articles/equipment-parents-disabilities>).

Suggestions: Peer support groups or DPOs; Sling library; Infant feeding group

3. Giving time, space and support for decisions

When providing information that ultimately requires a decision by the person, it is important to ensure that they have had sufficient time to process the information given and that they have had time to respond with any questions they may have. Some people may wish to bring a support person with them to appointments. 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.

Communicate directly with the disabled person

It is vital that practitioners always speak directly to the disabled person about their appointment, not to their supporter. If a practitioner has concerns about supporters exerting pressure or undue influence on the disabled person to make decisions, they should try to communicate with the disabled person alone to ascertain if the person is providing informed consent.

Define the role of the supporter

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 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 professional'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.

Provide a timeline for decisions and give support

It may be the case that a person does not understand the information that you have provided to them and is not making a decision about what to do next. If the person has come to their appointment unaccompanied, you can suggest that they reschedule the appointment and next time bring a trusted person who can support them in processing the information and helping them to make a decision. A trusted supporter can be the link between the information that the person is getting and the processing of what is important to the person. It is often the case that people can become overwhelmed with information and spend a lot of time weighing up options and the potential consequences of their choices. It is important to provide a clear timeline for making decisions and informing the person of all the different consequences of different actions so that they can make a fully informed decision. If you still don't get a decision from the person and you think you have done all you can do, then ask the person what else they can suggest.

- Can you connect them to a peer support organization?
- Do they need to talk to someone else who will understand, perhaps someone outside their family or service provider network?

Concerns about decision-making

There may be scenarios where you become concerned that the person is under undue pressure from someone else to make a particular decision, or that it cannot be established what their will and preferences are, or that you know their will and preferences but you fear the decision they want to make will cause harm. If you intend to involve a third party to assist in any of these scenarios you must communicate this with the person directly and act in accordance with your professional duty of ethics to retain the trust of the person to whom you are providing a service.

Under the new Assisted Decision Making (Capacity) Act 2015, the Decision Support Services (DSS) will be able to review and investigate complaints about decision supporters and decision support arrangements.

Respecting and implementing the decision and follow-up

When you have done your part to explain the circumstances and consequences of a decision, when the person has understood that information and has come to a clear decision, then that decision is to be respected regardless of the outcomes it produces. It is your role to implement the persons will and preferences as decided by the person, or with the assistance of a chosen or appointed support person.

4. Resources

Resources for communication

Some measures to make information accessible are simple to achieve. Others require specialist knowledge or equipment. The information below provides links to special services as well as to resources that will help equip you to create your own accessible documentation.

ISL interpreting

The Irish Deaf Society can teach you how to book an Irish Sign Language interpreter (<https://www.irishdeafociety.ie/interpreters/booking-an-interpreter>), while the Irish Remote Interpreting Service (IRIS) provides a booking service for remote sign language interpreters: <https://slis.ie/iris>.

Braille

The National Council for the Blind Ireland (NCBI) has a commercial Braille production service which can reproduce materials in a range of accessible formats including audio, Braille and large print: <https://www.ncbi.ie/supporting-you/everyday-living/library>.

Screen-reader accessibility

Learn how to make information available in electronic formats that are accessible to blind and visually impaired people and others who use screen-reader technology. Word documents work best. If you offer information for download on your website, it is recommended that both Word and pdf versions of files are made available.

- Microsoft has an explainer on how to make Word documents accessible: <https://support.microsoft.com/en-us/office/make-your-word-documents-accessible-to-people-with-disabilities-d9bf3683-87ac-47ea-b91a-78dcacb3c66d>.
- For pdfs, Adobe has support for how to create and modify tagged pdfs: <https://accessible-pdf.info/basics/acrobat/create-and-modify-pdf-tags-in-acrobat>.

Plain English

The National Adult Literacy Agency (NALA) has resources for making information about your service available in a jargon-free format like Plain English: <https://www.nala.ie/publications/writing-and-design-tips>.

Easy-to-Read English

People with an intellectual disability or people with limited literacy can be supported by making information available in Easy to Read formats. Inclusion Ireland has created guidelines to support you to convert your own documents into a more accessible format: <https://inclusionireland.ie/wp-content/uploads/2020/10/makeiteasyguide2011.pdf>.

Social Stories

A Social Story is a step by step guide that provides a walkthrough of your service. It can be in written, audio, illustrated or video format. AsIAm has a video explainer of how to create a social story on their website. Social Stories were developed for use by autistic people but can assist anyone who requires detailed information about a service: <https://asiam.ie/create-social-story-business-organisation>.

For a good example of clear communication, visit the Irish Family Planning Association video on early abortion care: <https://www.youtube.com/watch?v=XrQarH3ktDs%20>.

Resources for improving accessibility

The HSE National Guidelines on Accessible Health and Social Care Services are available here: <https://www.hse.ie/eng/services/yourhealthservice/access/natguideaccessibleservices/part1.html> .

The National Council for the Blind of Ireland has developed specific information resources for healthcare professionals, which can be accessed at <http://www.ncbi.ie/information-for/healthprofessionals>.

The National Disability Authority (NDA) has guidance on how to make websites accessible. <http://www.universaldesign.ie/useandapply/ict> .

Independent advocacy

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.patientadvocacyservice.ie>.



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