

# Supporting decision making

in reproductive and sexual health for people with disability



A tool to assist **clinicians** in supporting the decision making of clients with intellectual disability



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# Disability Resource Collection

Family Planning NSW has an extensive Disability Resource Collection available for loan to people with intellectual disability and their support people, including parents and carers, disability workers, clinicians and students.



The collection can be accessed in person at our Ashfield centre or across NSW through our mail delivery service. Membership fees apply for borrowing from this service.

Visit our website to view the Disability Resource Collection catalogue or to join as a collection member.

**P:** 02 8752 4388 | **E:** [healthpromotion@fpnsw.org.au](mailto:healthpromotion@fpnsw.org.au)

**W:** [www.fpnsw.org.au/disability](http://www.fpnsw.org.au/disability)

328-336 Liverpool Road, Ashfield 2131

## Shop

The Family Planning NSW Shop has a range of disability resources, available for sale, that are used by people with intellectual disability, disability workers, and parents and carers of people with intellectual disability.



**P:** 02 8752 4307 | **E:** [shop@fpnsw.org.au](mailto:shop@fpnsw.org.au) | **W:** [shop.fpnsw.org.au](http://shop.fpnsw.org.au)

# How to use this tool

Everyone has the right to make their own decisions about their reproductive and sexual health. This includes people with intellectual disability.

Clinicians have a responsibility to assist clients to make decisions, not to make the decision for them. There may be many issues to consider and it is not always easy for the clinician to think about the important decision making factors during the consultation. This tool is designed to assist this process. This tool can help clinicians support a client to have increased capacity to make their own decision in a specific situation.

## Assisting someone to make a decision requires a clinician to:

1. Be clear what decision/s needs to be made by the client
2. Know what the main factors of that decision are
3. Find out what the client already knows about the decision to be made
4. Provide information to assist the decision making by using plain language, diagrams and fact sheets

This tool does not replace clinical management guidelines. It is designed to supplement clinical guidelines by focusing on aspects of decision making that may be of particular importance to a client with intellectual disability.

Plain language has been used in this tool that the clinician may want to use with a client in a consultation.

## How to use this tool:

1. Clarify the decision/s that needs to be made with the client. If there are a number of decisions, assist with one at a time
2. Select the scenario most relevant to the decision being made
3. Refer to the decision making factors and use these as a guide for discussion. There may be additional factors specific to the client
4. Use the strategies and resources listed to support the client to make the decision

## There are six decision making scenarios in this series:

1. Whether to have sexual intercourse
2. Whether to have STI testing today
3. What type of contraception to use
4. Whether to have a Cervical Screening Test today
5. Whether to become a mother
6. What to do about an unintended pregnancy

*"A good decision supporter tells you stuff...but still lets you decide what to do. A bad decision supporter tells you what to do." (Self-advocate)*

# Tips for effective communication

## Setting up the consultation

- Some clients will need permission from the clinician to make their own decision. They may be compliant or feel the clinician has authority
- See the client alone for at least part of the consultation
- Carers or support people can be included if the client agrees
- Get support to assist with communication when necessary
- Ensure there are no interruptions

## Timing

- Provide a longer appointment
- Find out if there is a preferred time of day when the client is more alert or less tired
- If the client's ability to make a decision is likely to improve in the near future delay the decision if possible

**Information about substitute decision making and guardianship is provided at the back of this tool.**

## Facilitating the discussion

- Ask the client how they are feeling and address any anxieties. This will help put the person at ease and assist with communication
- Address questions directly to the client
- Use plain language and correct body terms
- Speak at a measured volume and speed
- Ask permission to discuss sexuality issues e.g. 'I need to ask you some questions about your sexual health. Is that ok?'
- Break down information into smaller parts
- Ask open ended questions
- Repeat information and check understanding
- Use health information resources
- Draw or show diagrams
- Practice a skill e.g. demonstrate using a condom, or saying 'no' to unwanted touching

## Finishing the consultation

- Give the client and their support person a fact sheet or other resources to take home
- Often one appointment won't be enough. Plan additional appointments as needed

# Sexual intercourse

## Decision to be made by client

### Whether to have sexual intercourse?

#### Example scenario:

A 22 year old woman with mild intellectual disability is asking about contraception. However, she is not sexually active. She says that her 24 year old boyfriend wants to have sex but she isn't sure whether she wants to.

This tool is designed to be used with people who meet the legal age of consent for sexual intercourse.

## Decision making factors

Everyone has the right to decide if they want sex and who they have sex with as long as both people are of consensual age.

Sexual intercourse can include oral, vaginal and anal sex.

Having sex can make a person feel good:

- it can make them feel intimate or close to another person
- it can make them feel relaxed and happy

Having sex can make a person feel bad:

- a woman might get pregnant when she doesn't want to
- a person might catch a sexually transmissible infection (STI)
- a person might have sex they don't enjoy

Some people decide not to have sex and that is OK.

If a person doesn't want sexual intercourse, there are other types of sexual touching such as hugging, kissing and masturbating together.

## Strategies to support decision making

Ask the client what they already understand about sex.

Discuss consent:

- both people must understand what sex is and what they are agreeing to
- both people must want to have sex and say 'yes'
- a person can say or signal 'stop' at any time during sex even if they agreed to it at the beginning
- a person must stop if the other person tells or signals them to
- a person must not pressure or threaten another person to have sex with them

Discuss the importance of communication with sexual partners including what type of sex each person wants or doesn't want.

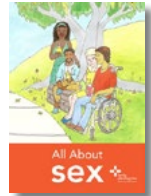
Discuss safe sex including condoms, lubricant and where to access them.

Teach the steps of putting on a condom using a demonstration model.

Discuss the range of contraception options available. Refer to the scenario: *What type of contraception to use.*

## Resources

All About Sex fact sheets (Relationships, Having Sex, Safe Sex and Sexually Transmissible Infections) Available from Family Planning NSW Shop and online [www.fpnsw.org.au/allaboutsex](http://www.fpnsw.org.au/allaboutsex)



Sex, Safe and Fun resources Support person's guide and learner's booklets Condom pack [www.fpnsw.org.au/sexsafeandfun](http://www.fpnsw.org.au/sexsafeandfun)



Penis demonstration model Available for loan from the Family Planning NSW Disability Resource Collection [www.fpnsw.org.au/disability](http://www.fpnsw.org.au/disability)



Being a Healthy Woman fact sheets (Close Relationships and Sex, Safer Sex) [www.fpnsw.org.au/beingahealthywoman](http://www.fpnsw.org.au/beingahealthywoman)



Family Planning NSW Talkline 1300 658 886 for unbiased information and referral [www.fpnsw.org.au/talkline](http://www.fpnsw.org.au/talkline)



# STI testing

## Decision to be made by client

### Whether to have STI testing today?

#### Example scenario:

A 24 year old man with intellectual disability and limited literacy skills is accompanied by a carer who suggested this visit. He is sexually active with both genders. He knows little about STI tests including HIV.

## Decision making factors

It is one of the ways a sexually active person looks after themselves and stays healthy.

The doctor or nurse will ask private questions about a person's sexual activity.

The tests can detect infections. The infections can be treated.

A person can take swabs from themselves or do a urine test. Other tests could involve a physical check-up of private body parts.

A person can ask the doctor or nurse to stop at any time.

A person may need to come back for discussion of results, treatment and/or follow up tests.

The treatment can cure the STI or prevent further problems.

If there is an infection, sexual partners may need to be told.

A person can ask for a female or male doctor or nurse.

A person can make a decision today or can come back later.

A person can decide not to have a test.

## Strategies to support decision making

Ask the client what they already know about STIs and testing.

Describe the process :

- how to self-swab
- clinician collected swab
- urine sample
- blood tests with needles
- samples sent to lab and results within one week

Show equipment or use a picture.

Discuss confidentiality.

Discuss privacy and show the curtain and modesty sheet.

Discuss support – family or friend can attend if wanted.

Introduce clinic chaperone if there is one.

*STI testing provides an opportunity to talk to the client about safe sex.*

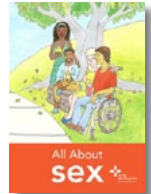
## Resources

### All About Sex fact sheets

(A Woman's Body, A Man's Body, Safe Sex and Sexually Transmissible Infections, Private Body Parts – Keeping them healthy)

Available from Family Planning NSW Shop and online

[www.fpnsw.org.au/allaboutsex](http://www.fpnsw.org.au/allaboutsex)



### Diagrams of male or female body parts



Swab sticks, urine jar

### Sex, Safe and Fun resources

Condom pack

[www.fpnsw.org.au/sexsafeandfun](http://www.fpnsw.org.au/sexsafeandfun)



### Being a Healthy Woman fact sheets

(Safer Sex)

[www.fpnsw.org.au/beingahealthywoman](http://www.fpnsw.org.au/beingahealthywoman)



### Family Planning NSW Talkline

1300 658 886 for unbiased information and referral

[www.fpnsw.org.au/talkline](http://www.fpnsw.org.au/talkline)



# Contraception

## Decision to be made by client

### What type of contraception to use?

#### Example scenario:

*A woman with a mild intellectual disability who is in a consensual sexual relationship with her male partner wants to avoid pregnancy and wants to discuss her options for contraception.*

## Decision making factors

Some types of contraception are permanent. Some last a long time – from three months up to 10 years.

Some types of contraception need to be taken every day.

Different types of contraception can be:

- swallowed as a pill every day
- put into the vagina by the woman
- injected into the arm or buttock by a nurse or doctor
- implanted under the skin of the arm by a nurse or doctor
- put into the uterus by a doctor or nurse

Some types of contraception cost more than others.

The woman and her partner might still be advised to use condoms to prevent STIs.

## Strategies to support decision making

Assess the needs of the client and contraindications to any types of contraception. Eliminate these from the decision making.

Discuss remaining types of contraception in relation to how they are taken or procedures needed. Show samples and demonstrate using diagrams and models.

Eliminate types of contraception that are unacceptable to the client from the decision making process.

Discuss the remaining types of contraception in more detail:

- fitting in with existing or new medication regimes
- costs
- effectiveness of long acting reversible contraception (LARC)
- side effects
- additional non contraceptive benefits

Discuss whether there is a need to use condoms for STI protection.

## Resources

Know Your Health: Contraceptive Options z-card  
[www.fpnsw.org.au/non-english-speaking](http://www.fpnsw.org.au/non-english-speaking)



All About Sex fact sheets (Contraception, Safe Sex and Sexually Transmissible Infections)  
Available from Family Planning NSW Shop and online  
[www.fpnsw.org.au/allaboutsex](http://www.fpnsw.org.au/allaboutsex)



Being a Healthy Woman fact sheets (Safer Sex)  
[www.fpnsw.org.au/beingahealthywoman](http://www.fpnsw.org.au/beingahealthywoman)



Family Planning NSW Contraceptive Kit or samples of types of contraception - Implant, IUDs, Pill, injection, vaginal ring. Available at Family Planning NSW Shop  
[shop.fpnsw.org.au/contraceptive-kit](http://shop.fpnsw.org.au/contraceptive-kit)



Sex, Safe and Fun resources  
Condom pack  
[www.fpnsw.org.au/sexsafeandfun](http://www.fpnsw.org.au/sexsafeandfun)



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[www.fpnsw.org.au/talkline](http://www.fpnsw.org.au/talkline)





# Cervical Screening Test

## Decision to be made by client

### Whether to have a Cervical Screening Test today?

#### Example scenario:

*A 26 year old woman with intellectual disability and limited literacy skills is accompanied by a carer. She has been sexually active for two years. She knows little about the Cervical Screening Test and is unsure if she has had one before. She is undecided whether to have one now.*

## Decision making factors

It is one of the ways a woman who has ever been sexually active looks after herself and stays healthy.

It is recommended that women aged 25-74 years of age have a Cervical Screening Test every five years.

The Cervical Screening Test detects human papillomavirus (HPV) infection, which is the first step in developing cervical cancer.

Women who do not have a Cervical Screening Test have a risk of developing cancer.

It takes less than 10 minutes. There may be discomfort.

The test is usually done when a woman is not having her period.

There is a physical check-up of private body parts. The woman will need to remove her underpants. A speculum will be put inside her vagina so her cervix can be seen by the doctor or nurse.

She can ask for a female nurse or doctor.

The woman may need to come back for discussion of results and referral for follow up tests.

The woman can make a decision today or come back another day.

Women may be eligible for self-collection. It still needs to be done in the clinic and cannot be done at home.

## Strategies to support decision making

Ask the client what they already know about having a Cervical Screening Test.

Describe the process:

- use of speculum
- sample sent to lab
- results in 1 - 3 weeks

Show equipment and demonstrate with a model or use a picture.

Use the easy English resource 'Betty's Story' to explain the procedure.

Discuss privacy and show the curtain and modesty sheet.

Explain that she can ask the nurse or doctor to stop at any time.

Discuss support – family or friend can attend if wanted.

Introduce clinic chaperone if there is one.

Explain that she can go on the National Cancer Screening Register or she can nominate a representative for the Register. She will have a letter sent to her address. She can decide not to go on the Register.

## Resources

### Betty's Story

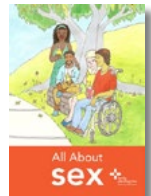
Easy English social story of Betty having the Cervical Screening Test  
[www.fpnsw.org.au/justchecking](http://www.fpnsw.org.au/justchecking)



### All About Sex fact sheets

(Private Body Parts - Keeping them healthy)

Available from Family Planning NSW Shop and online  
[www.fpnsw.org.au/allaboutsex](http://www.fpnsw.org.au/allaboutsex)



### Diagram of female body parts

### Pelvic model and speculum brush, slide and light

### Family Planning NSW Talkline

1300 658 886 for unbiased information and referral  
[www.fpnsw.org.au/talkline](http://www.fpnsw.org.au/talkline)



# Becoming a mother

## Decision to be made by client

### Whether to become a mother?

#### Example scenario:

A 30 year old woman with intellectual disability lives independently with support from a paid worker each day. She is sexually active. She has come for a routine check-up and wants to talk about becoming a mother.

## Decision making factors

Some women will want to be a mother. Some women do not want to be a mother. It is important for the woman to decide for herself.

There are many things to consider to make a decision to have a baby.

It is important for a woman to look after her health if she wants to have a baby.

A pregnancy lasts for nine months. Being pregnant will mean a woman has a lot of physical changes.

Being a mother can be enjoyable. It is also hard work.

It is important that a woman can care for a child. A child needs to be looked after, fed, bathed, dressed, played with, talked to, helped to sleep, and watched over every day. This will mean a change in lifestyle for the woman.

Other people need to help. This may be a partner, family or paid workers.

The child will need a safe home to live in.

The baby will grow up. He or she will become a child, then a teenager, then an adult. They will need different things at different ages.

## Strategies to support decision making

Ask the client if she can talk with anyone who has children to learn more about being a mother.

Discuss the good things and difficult things about being a mother.

Ask who can support her if she decides to become a mother.

Talk about changes she would experience during pregnancy.

Discuss pre conception and pregnancy care including folate, diet and exercise, alcohol, smoking, medications.

Explain that if she is having sex, she can use contraception to give her time to make the decision.

Discuss her choice of contraception until making her decision. Refer to the scenario: *What type of contraception to use.*

Ask who else she can talk to about this decision.

## Resources

All About Sex fact sheets (Planning Pregnancy and Pregnancy Choices, Pregnancy and Birth) Available from Family Planning NSW Shop and online [www.fpnsw.org.au/allaboutsex](http://www.fpnsw.org.au/allaboutsex)



Being a Healthy Woman fact sheets (Deciding to Become a Parent, Being Pregnant) includes questions to consider before becoming pregnant [www.fpnsw.org.au/beingahealthywoman](http://www.fpnsw.org.au/beingahealthywoman)



Healthy start website Resources, tools and training for supporting parents with intellectual disability [www.healthystart.net.au](http://www.healthystart.net.au)

Pregnancy birth and baby website [www.pregnancybirthbaby.org.au/being-a-mother](http://www.pregnancybirthbaby.org.au/being-a-mother)

Family Planning NSW Talkline 1300 658 886 for unbiased information and referral [www.fpnsw.org.au/talkline](http://www.fpnsw.org.au/talkline)



# Unintended pregnancy

## Decision to be made by client

### What to do about an unintended pregnancy?

#### Example scenario:

A 23 year old woman with intellectual disability has had a positive pregnancy test and was not planning a pregnancy. She is unsure if she wants to continue the pregnancy.

## Decision making factors

There are three options available for a woman with an unintended pregnancy:

1. Continue the pregnancy and parent
2. Continue the pregnancy and foster or adopt the child out
3. Terminate the pregnancy through abortion

Continuing a pregnancy and being a parent is a big responsibility and can be very challenging. Refer to decision making tool: *Whether to become a mother*

Giving a child up for adoption is permanent. Fostering can be short or longer term.

The stage of the pregnancy determines the options for abortion type: surgical or medical, and the cost of abortion.

Abortion is safer and less expensive if done before 12 weeks gestation but may occur at a later time if needed.

A decision does not always need to be made immediately.

A woman's personal circumstances including her belief system and supports may play an important role in her decision.

## Strategies to support decision making

Help the client explore and weigh up each option using the resource *Pregnant: Working through your options*.

Explain that she does not need the man's permission to terminate or continue a pregnancy but his consent is necessary for adoption.

Discuss support that she has available to her to help make her decision and to manage that decision.

Explain that if she wants further support with her decision, counsellors are available.

Discuss the relevant services that can provide support as referenced in *Pregnant: Working through your options*.

## Resources

### Know Your Health: Pregnancy Options

Available from the Family Planning NSW Shop and online [www.fpnsw.org.au/health-information/individuals/pregnancy](http://www.fpnsw.org.au/health-information/individuals/pregnancy)



### All About Sex fact sheets (Planning Pregnancy and Pregnancy Choices)

Available from the Family Planning NSW Shop and online [www.fpnsw.org.au/allaboutsex](http://www.fpnsw.org.au/allaboutsex)



### Children by choice website

[www.childrenbychoice.org.au/](http://www.childrenbychoice.org.au/)

### Being a Healthy Woman fact sheets

(Deciding to Become a Parent) [www.fpnsw.org.au/beingahealthywoman](http://www.fpnsw.org.au/beingahealthywoman)



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[www.fpnsw.org.au/talkline](http://www.fpnsw.org.au/talkline)



# Substitute decision making and guardianship

The purpose of this tool is to assist the clinician to improve a client's ability to make a decision. If the client has received information over an appropriate time period and in a relevant format and they still do not have the ability, as a last resort a 'Person Responsible' may be needed to make a decision.

## The Person Responsible hierarchy is:

- A guardian, appointed by the Guardianship Division or a legally appointed enduring guardian. If no such person then
- A spouse or de facto including same sex partner. If no such person then
- An unpaid carer (i.e. a person not employed as a carer). If no such person then
- A close relative or friend

The Person Responsible can only give consent specific to the treatment proposed, not general consent for all medical treatment.

If the Person Responsible makes a decision on behalf of the client but the client objects, consent cannot be given and treatment should not proceed.

If there is no Person Responsible or the client objects to treatment, an application can be made to the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT).

## Guardians:

- Are appointed by the Guardianship Division of NCAT
- Can be a relative or friend of the client
- Can be the Public Guardian – a staff member of the Office of Public Guardian
- Must seek the person's views and have limited decision making authority – ask them what they have been authorised to do

**No one should ever make a decision for a person without seeking their views and wishes.**

Read the fact sheet 'Person Responsible'  
[www.publicguardian.justice.nsw.gov.au](http://www.publicguardian.justice.nsw.gov.au)

Call the Public Guardian Information and Support Line on (02) 8688 6070 or email [informationsupport@opg.nsw.gov.au](mailto:informationsupport@opg.nsw.gov.au) to seek information about specific situations.

Read the fact sheet 'Consent to Medical or Dental Treatment' [www.ncat.nsw.gov.au](http://www.ncat.nsw.gov.au)

## OUR CLINICS

### Family Planning NSW Ashfield

328-336 Liverpool Road  
Ashfield NSW 2131  
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T 02 8752 4316 (Clinic)  
F 02 8752 4392  
ABN 75 000 026 335

### Family Planning NSW Fairfield

24-26 Nelson St  
Fairfield NSW 2165  
T 02 9754 1322  
F 02 9723 0922

### Family Planning NSW Dubbo

2B/155 Macquarie Street  
Dubbo NSW 2830  
T 02 6885 1544  
F 02 6882 3666

### Family Planning NSW Hunter

Ground floor,  
384 Hunter St  
Newcastle NSW 2300  
T 02 4929 4485  
F 02 4926 2029

### Family Planning NSW Penrith

13 Reserve Street  
Penrith NSW 2750  
T 02 4749 0500  
F 02 4731 6787

## About Family Planning NSW

Family Planning NSW is the leading provider of reproductive and sexual health services in NSW. We are experts on contraception, pregnancy options, sexually transmissible infections (STIs), sexuality and sexual function, menstruation, menopause, common gynaecological and vaginal problems, cervical cancer screening, breast awareness and men's health.

We have five fixed clinics in NSW (Ashfield, Fairfield, Penrith, Hunter and Dubbo) and use innovative partnerships to deliver services in other key locations across the state with more than 28,000 client visits annually. We also operate a confidential telephone and email information and referral service, connecting our expertise to communities across NSW.

We provide information and health promotion activities, as well as education and training for doctors, nurses, teachers, and other health, education and welfare professionals.

### Our work with people with disability

We provide education and training for teachers, disability workers, clinicians, family members and carers about sexuality for people with intellectual disability. Our clinics are a safe place for people with disability to talk about intimate and sometimes challenging issues and to access confidential reproductive and sexual healthcare. We also produce innovative easy to read resources to support our professional and community education activities.

Our work aligns with the priorities of people with a disability and organisations that support them. Family Planning NSW has been delivering targeted services to people with disability for more than 35 years.

For more information about our disability program go to [www.fpnsw.org.au/disability](http://www.fpnsw.org.au/disability)

[www.fpnsw.org.au](http://www.fpnsw.org.au) | [talkline 1300 658 886](tel:1300658886) | [Shop](#)

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