Providing Disability Inclusive Care For Pregnant Women

A WORKSHOP FOR MIDWIVES

FACILITATOR'S REFERENCE MANUAL



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Overview

INTRODUCTION

More than 1 billion people, 15% of the global population, live with a disability and a worldwide disability prevalence of 10% has been estimated among women of childbearing age (Malouf et al. 2014). Many women with a disability want to have children and are capable of conceiving but face considerable pressure not to do so. If they do become pregnant and give birth, they may face negative attitudes and scepticism regarding their ability to parent effectively. Barriers in access to health care providers and facilities have been reported for many women with disabilities (Blair et al. 2022), with increased adverse pregnancy outcomes being reported compared to mothers without disability. Additionally, women with disabilities are 2-4 times more likely to experience intimate partner violence than those without disabilities (Dunkle et al. 2018).

Workshop Rationale

This workshop is part of a series that UNFPA has developed to support midwives in caring for women and their families. Other workshops in the series include Caring for Adolescents in Pregnancy and Childbirth; Caring for Women Experiencing Gender-Based Violence During Pregnancy, Birth and Postpartum; and Respectful Maternity Care/Obstetric Violence.

UNFPA has identified a need to support midwives and other maternal health care providers to support the care of women who have a disability throughout their pregnancy, childbirth and postpartum period. In lowand middle-income countries resources and knowledge surrounding disability is often limited which can lead to poor outcomes for these women.

An accessible, easy-to-complete and relevant training package has been developed in line with available professional development guidelines.

Definition of Disability

While there is no universal agreement on a definition of disability, the International Classification of Functioning Disability and Health defines disability as: "an umbrella term, covering impairments, activity limitations, and participation restrictions....disability is a contextual variable, dynamic over time and in relation to circumstances; its prevalence corresponds to social and economic status. Disability is thus seen as a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives"

Scope of the Workshop

This workshop is designed to cover the most essential aspects of midwifery care for women with a disability during the perinatal period. Whilst it does include discussion around gender-based violence and respectful maternity care, it does not explore these in significant detail, and facilitators are expected to refer to the other modules in the series as a useful reference to inform the delivery of this content.

Intersections of Disability, Gender, Violence and Disrespect

- In low and middle-income countries, women with disabilities are 2-4 times more likely to experience intimate-partner violence than women without disabilities
- · Disability also increases women's risk of nonpartner sexual violence
- The risk of both intimate partner violence and non-intimate partner violence increases with the severity of disability
- Women with disabilities experience high levels of stigma and discrimination, compounding their risk of intimate partner violence and reducing their ability to seek help
- Women with disabilities report negative experiences with health care providers when they seek care at health care facilities and in the community

(Dunkle at al. 2018)

How to Use this Workshop Toolkit

The workshop toolkit is designed as an adaptable resource for countries to present to midwives and other maternal health care providers to guide best practice when caring for women with disabilities during pregnancy, birth, the postnatal period and for the essential component of providing safe and effective family planning. It is comprehensive in breadth, flexible to embed country contexts and has multiple globally validated resources to support implementation.

The workshop content is divided into 4 modules which can be delivered as a one-day workshop, two half-day workshops, or in individual modules over a period of time. The modules are outlined below.

There are three documents and a resource folder that facilitators will use to deliver this workshop. All are aligned and have multiple prompts to help deliver the content and explain the activities:

- 1. The Facilitator's Reference Manual, this document. This contains the evidence-based information that makes up the content of the workshop. Facilitators will need to be familiar with this material prior to commencing delivering the workshop and refer to it as they progress through the 4 modules. It contains references and learning materials to support evidence-based understanding of caring for women with disabilities who are pregnant.
- The Workshop PowerPoint Presentation contains 64 slides that cover all 4 modules. The slides have accompanying speaker notes that contain brief key points to prompt the facilitator in explaining the issues and support the activities.
- 3. The Facilitator's Guide for PowerPoint Presentation is a quick-reference, step-by-step guide of each slide and activity to support the overall delivery of the workshop. The guide includes estimated timings for each slide and activity and will assist facilitators in planning their workshops.
- 4. The **Resource Folder** contains useful resources to support each module. These resources include recent global reports, key documents and resources for running the activities in the workshop.

Modules Overview

Module 1: Background to Caring for Women with a Disability

The first module introduces the key considerations for women with a disability who become pregnant. It delves into what a disability is, recognising that sometimes disability is not immediately obvious. It is important that midwives understand the impact of a disability on pregnancies and the unique elements of midwifery care that are required when caring for women with a disability in the perinatal period.

The first module suggests incorporating an additional activity to support midwives in preventing stigma and prejudice by self-identifying any negative perceptions they may have of pregnant women with a disability. These negative perceptions can have a direct impact on how a woman with a disability is treated in the clinical setting.

Module 2: Antenatal Care

Module 2 focuses on care needed during the antenatal period and introduces participants to the concept of a *Woman with Individual Needs (WIN) Clinic*. Participants will meet Lola, a 27-year-old pregnant woman with an intellectual and physical disability who presents to the clinic. Participating midwives will learn about how to incorporate a WIN Clinic into their regular ANC and develop a collaborative care plan for Lola's specific needs, while learning about the specific considerations Lola will need to have a safe and supported pregnancy.

Module 3: Labour and Birth

Module 3 brings the workshop's focus to care during labour and birth and the key considerations for looking after a woman with a disability in labour and childbirth. Participating midwives follow Lola into her labour as the clinical scenario evolves.

Module 4: Postnatal and Family Planning

The final module focuses on postpartum care of mothers with a disability and the importance of postpartum Family Planning. This module explores Lola's scenario in the early postnatal period, and participating midwives will develop a detailed postpartum care plan for Lola and her baby. Module four contains information on Family Planning counselling, along with an important focus on informed consent.



Case Study and Prompts

Having provided workshop participants with the background and information about the key points of caring for pregnant women with a disability, the workshop progresses through each module with a case study involving Lola and her family. With each stage of Lola's scenario, facilitators are prompted to encourage group discussion with regard to Lola's clinical and psychosocial care. Facilitators are prompted with the questions below to guide the discussion about how to best care for Lola as a woman with a disability.

> What else do you need to know? What are your concerns at this stage? What are your priorities? What is your care plan for Lola?

Facilitators will find additional prompts for group discussions and detailed activities within the slide presenter's notes and within this reference manual.

The progression of Lola's childbearing experience allows for opportunities of critical thinking, decision making, and considerations of the complexities and risks associated with a mother who has a disability. The toolkit provides a step-by-step series of activities to engage participating midwives and emphasizes the strong need for sensitive, empathetic, and respectful care of Lola.

Respectful Maternity Care

Facilitators are encouraged to remind participants of the importance of Respectful Maternity Care at each encounter with Lola. Respectful Maternity Care practice points are embedded throughout the workshop modules. See example below.

Essential respectful care practice points

- Gently welcome Lola to the clinic and explain the process of this visit with her and her mother
- Seek consent from Lola before any physical examination
- Always speak warmly to her and advise of what and why you are doing midwifery tasks
- Always share the information of your findings with Lola





Additional activity - Self-Reflection on Personal Beliefs and Values

Facilitator Guidance:

A values clarification exercise to support midwives in preventing stigma and prejudice is suggested to identify negative perceptions of women with a disability who become pregnant. These negative perceptions are usually not conscious but can have a direct impact on how women with disabilities are treated in the clinical setting. It is preferable to ask the following questions in a confidential questionnaire to ensure an accurate response from the midwives.

This self-reflection activity may be challenging for some midwives, and therefore is an optional activity. It should be confidential and is not intended to be shared. Hand out the questionnaire at the beginning of the workshop and ask participants to respond to the statements about maternity care for women with a disability.

The midwives can be encouraged to return to this questionnaire after completing the course to reflect on their initial responses. This may prompt the midwives to consider how their attitudes can impact on the experience of a pregnant woman with a disability in their care.

Each question asks for a response: Agree, Neutral, Disagree. Participants mark one answer per question.

Values Clarification Ouestionnaire

This questionnaire is confidential. Answers will not be shared with anyone. Do not write your name on the questionnaire.

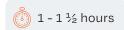
Mark each question with one answer: agree, neutral or disagree. There is no right or wrong answer.

	Agree	Neutral	Disagree
Women with a disability should not become pregnant			
If a woman with a disability has a baby, she will not be a good mother			
I feel uncomfortable caring for a pregnant woman with a disability			
Pregnant women with a disability do not require different pregnancy care than women without a disability			
Women with a physical or intellectual disability should be offered a caesarean section as they will have difficulty in labour and childbirth			
If a woman with a disability has a baby, she will be a burden on her family and society			
Women with a disability should be given a permanent non-reversible method of family planning/contraception, such as tubal ligation			

Module 1

Background to Caring for a Woman with a Disability





Introduction

More than 1 billion people, 15% of the global population, live with a disability (WHO 2022). A worldwide disability prevalence of 10% has been estimated among women of childbearing age (Malouf et al. 2014).

There is no universal agreement on the definition of a disability. The UN General Assembly, Convention on the Rights of Persons with Disabilities Resolution 2007, adopted the definition of a person with a disability as those who have "long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UN 2007). The International Classification of Functioning Disability and Health defines disability in broader terms as:

"an umbrella term, covering impairments, activity limitations, and participation restrictions....disability is a contextual variable, dynamic over time and in relation to circumstances; its prevalence corresponds to social and economic status. Disability is thus seen as a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives".1

People with a disability are diverse, and factors such as sex, age, gender identity, sexual orientation, religion, race, ethnicity and economic situation affect their experiences in life and in their health needs. However, overall people with a disability die earlier, have poorer health, and experience more limitations in everyday functioning than people without a disability (WHO 2023).

The WHO Disability-Inclusive Health Services Training Package² is a training toolkit to support greater inclusion of people with a disability into health care services. These modules listed below about general disability-inclusive care can be used as a companion to this training module.



MODULE 3, VIDEO 1

What are physically accessible health services and why are they important www.youtube.com/watch?v=eVhJqAsylgY



MODULE 3, VIDEO 2

How to make your health service physically accessible www.youtube.com/watch?v=xgdwKV8R0CE



MODULE 4, VIDEO 1

Understanding communication barriers www.youtube.com/watch?v=XTq9a4VIE_A



MODULE 4, VIDEO 2

Strategies and good practices in disabilityinclusive communication in health care www.youtube.com/watch?v=hnzAyGdGwjQ

¹ https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

² https://iris.who.int/bitstream/handle/10665/369694/9789290620020-eng.pdf?sequence=1

Use of Language

Choice of language has an impact on the way people with a disability are perceived in society. Language is a powerful tool that can challenge and change stereotypes and attitudes. Using "person first" language emphasises the person, not the disability. Recommended ways of talking about people with a disability include:

- · Women with disabilities
- Lola lives with a disability
- Lola has a disability.

(Disability Australia 2024)

However, it is important to respect the individual's choice about the language that they use about themselves. Some people may choose to say "I am a disabled person". In this toolkit, "women or people with disabilities" or "a woman living with a disability" are the terms used.

Classification of Disability

Disabilities vary in their etiology and impact but they can be broadly classified based on common activity limitations (Tarasoff et al. 2020). Disability may be acute or long-term, progressive or stable, and need to be considered in terms of the physical implications in daily life and in relation to a person's coping ability and those of their family (Redshaw, 2013). Classifications of disability include:

- 1. Physical disabilities such as cerebral palsy, paraplegia/quadriplegia, amputations and loss of limbs, achondroplasia (dwarfism), osteomalacia (rickets), complications of severe burns (resulting in contractions of limbs), spina bifida and spinal cord injuries are those associated with limits to mobility, flexibility and dexterity.
- 2. Sensory disabilities such as vision and hearing impairments.
- 3. Severe mental health conditions such as schizophrenia, severe forms of bipolar disorder, and major depressive disorders that can cause prolonged impairments and interference in daily life and therefore can be classified as a disability. These conditions are complex as they can often be unobservable, are highly stigmatised, tend to fluctuate, and if well controlled, may have only a minimal direct relationship to functional status (Drake et al. 2011).
- 4. Intellectual and developmental disabilities such as Down Syndrome and other genetic conditions; complications from infections acquired during pregnancy, such as rubella, congenital iodine deficiency syndrome, or malnutrition; exposure to diseases in childhood like whooping cough, measles or meningitis; exposure to toxins such as lead, mercury and alcohol during pregnancy; and, autism spectrum disorder. These are all associated with limitations in adaptive and cognitive functioning.

International Frameworks

Countries have an obligation under international human rights law, and in some cases domestic laws, to address the health inequities faced by people with a disability. There are two international frameworks which relate to health equity for persons with a disability:

1. The Convention on the Rights of Persons with Disabilities³

This convention requires state parties to ensure that people living with a disability have access to the same range, quality and standard or affordable health care as other people.

2. The World Assembly Resolution WHA74.8: The highest attainable standard of health for persons with disabilities⁴

This resolution calls for member states to ensure that people with disabilities receive effective health services as part of universal health coverage, equal protection during emergencies and equal access to cross-sectoral public health interventions.

Factors Contributing to Health Inequities for People Living with a Disability

The World Health Organization outlines four critical factors that contribute to health inequities for people who live with disability (WHO 2022).

1. Structural and Cultural Factors:

People with a disability can experience stigma and discrimination in all facets of their lives, which then affects their physical and mental health. Country laws and policies may deny people with a disability the right to make their own decisions and allow a range of harmful practices within the health sector, such as forced sterilisation, involuntary admission to and treatment in health facilities, and in some cases, institutionalisation. Additionally, in many cultures, disability has a long history of being perceived as a misfortune caused by a curse "from God" or associated with sins in a past life. This results in negative social attitudes and behaviours towards people with a disability and is expressed in ways such as exclusion from social roles and activities. People with a disability are then less likely to have access to education, employment, marriage, or to be allowed to participate in political and social events (Devkota et al. 2019). These cultural beliefs may also contribute to the increased levels of sexual and domestic violence that people with a disability are subjected to compared to people without a disability (Dunkle et al. 2018).

2. Social Determinates of Health:

Poverty, exclusion from education and employment, and poor living conditions can contribute to the greater risk of poor health and unmet healthcare needs among persons with a disability. Many people with a disability are reliant on support from family members to manage activities of daily living and to engage in health and community activities. This is not only a driver of disadvantage for people with a disability, but also their caregivers, who are mostly women and girls.

³ https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-Disabilities.html

⁴ https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

3. Risk Factors:

People with a disability are more likely to have risk factors for non-communicable diseases such as smoking, poor diet, alcohol consumption, and a lack of physical activity. There are also specific risk factors for pregnant women, which are discussed in the next chapter.

4. Health Systems:

People with a disability face barriers in all aspects of the health system, such as a lack of knowledge, negative attitudes and discriminatory practices amongst health care workers; inaccessible health facilities and information; and a lack of information or data collection and analysis on disability. These all combine to contribute to health inequities experienced by people living with a disability.

Pregnant Women with a Disability

Many women with a disability want to have children and have reproductive capacity (are capable of conceiving), but often face considerable pressure not to do so. If they do become pregnant and give birth, they may face negative attitudes and scepticism regarding their ability to parent effectively. A study of societal attitudes and behaviours towards women with disabilities in rural Nepal found negative societal attitudes and misconceptions about disability in relation to ability to conceive, give birth and safely raise a child (Devkota et al 2019). A recent study in Ghana reported two contrasting themes from health care providers towards caring for pregnant women with a disability: positive perceptions regarding the strength and determination of women with a disability to become pregnant, but also negative perceptions shaped by cultural biases questioning why these women would want to become pregnant (Obeng et al 2024). A survey of the health care experience of women with a disability revealed that a significant proportion felt their rights were poorly respected and that they were treated less favourably because of their disability. The authors recommended that there is a need to look more closely at individualised care for women with disabilities (Hall et al 2018).

Barriers in access to health care providers and facilities have been reported for many women with disabilities. Blair et al.'s (2022) scoping review found that for women with a disability, access to and experiences of maternity care is suboptimal and recommended that improving maternity providers disability knowledge and awareness, increasing the availability of support services, and increasing person-centred care through organisational policies and provider training may help to address the inequities women with disabilities face in accessing high-quality maternity care. A study in Uganda on people with physical disabilities accessing sexual and reproductive health services found a multitude of challenges, including negative attitudes of service providers, long queues at health facilities, high costs of services, unfriendly physical structures and perceptions from that people with a physical disability should be asexual (Ahumuza et al 2014).

Adverse outcomes for pregnant women with a disability have been reported across the literature. A large cohort study from 2002-2011 observed increased risks in women with intellectual and developmental disability for pre-eclampsia, venous thromboembolism, increased risks for preterm birth and small for gestational age babies (Brown et al 2016). A large, secondary analysis of a cohort of over 220,000 women in the United States of America reported that women with disabilities had a higher risk of maternal mortality (11 times the risk of dying), and more often experienced severe maternal morbidities, including severe pre-eclampsia/eclampsia, haemorrhage, fever, thromboembolism, cardiovascular events and infection (Gleason et al. 2021).

A study conducted in Australia, found the following occurrences in women with disabilities compared with the occurrence hospital wide (Smithson et all 2021):

Outcome	Occurrence in women with disabilities	Occurrence hospital wide
Pre-term birth	17%	4%
Caesarean section birth	52%	32%
Low birth weight baby	20%	9%
Baby required resuscitation at birth	35%	11%
Baby admitted to Special Care Nursery or Neonatal Intensive Care Unit	29%	13%
Baby received formula in hospital	54%	28%

A systematic review by Malouf et al (2014) found that there was a lack of published research on the effectiveness of healthcare interventions to improve outcomes for pregnant women with disabilities and their families and urged for more research in this area to be conducted. Goldacre (2016) also suggests that further work needs to be carried out to understand the mechanisms behind the adverse outcomes seen in pregnant women with a disability.

Module 2

Antenatal Care





Pre-Conception Care

SLIDE 21

A growing body of research shows that women with disabilities have disproportionally high rates of preconception risk factors, including diabetes, obesity, asthma, mental illness and exposure to violence - all of which are known risk factors for adverse perinatal outcomes (Tarasoff et al. 2021; Homeyard et al. 2016). Tarasoff et al. (2021) suggest that because medical care is often focussed on the person's disability, opportunities to address modifiable risk factors for pregnancy in a woman with a disability have not been routinely provided. Interventions in the pre-conception period would allow women with disabilities, their support people and health care providers to plan ahead in terms of what resources and supports they need, as well as counselling and advising women about issues such as medication use during their pregnancy, a concern that many women with a disability have reported (Smeltzer 2007). Midwives have a role to play in this area by advising women they see to seek care before they are planning their next pregnancy.

Antenatal Care

SLIDE 22-25

Women with disabilities have reported that health care providers' initial reactions to their pregnancy are that the pregnancy has been discouraged, assumptions that they have presented to terminate the pregnancy, or negative comments being made about them being irresponsible in considering pregnancy and motherhood (Smeltzer et al 2017). This is thought to be the reason why many women with a disability may delay seeking care during pregnancy or do not attend antenatal care all together, putting themselves and their babies at more risk. It is therefore of the upmost importance for midwives who are seeing women with a disability for the first time in the antenatal clinic to:

- 1. Acknowledge the woman with a disability's efforts to ensure a healthy pregnancy by presenting to the antenatal clinic, and
- 2. Avoid negative verbal and non-verbal responses to those who are already pregnant at the time of their first visit to a health care provider for pregnancy care.

Many women with a disability report difficulty finding a healthcare provider with experience in providing maternity care to women with disabilities (Alhulaibi et al 2024). Additionally, many healthcare providers report not having the resources and training they need to support women with a disability throughout pregnancy and the postpartum period (Alhulaibi et al 2024).

Midwives play a key role in providing care to pregnant women with disabilities, as they are likely to spend more time interacting with these women compared to other healthcare providers. Given the greater potential for poorer clinical outcomes for both women and their babies, it is imperative that midwives are able to recognise and address the needs of this demographic of women and families. Recent literature has concluded that when midwives provide pregnant women with a continuously caring environment during pregnancy, maternal satisfaction and improved outcomes are achieved (Alhulaibi et al 2024). However, it is acknowledged that the care of women with a disability can be challenging and often requires additional time, and excessive workloads, overcrowded waiting rooms and an overall lack of time to spend in consultations impact midwives' ability to provide quality care.

The WIN Clinic

SLIDE 26-27

Recognising the complexity of providing appropriate care to women with disabilities, some health services have now begun offering specialised clinics in maternity care sites, providing midwifery and medical care to pregnant women who have learning, intellectual, physical or sensory disabilities - these are sometimes called "Women with Individual Needs Clinics- WIN Clinics".5

Considerations for Setting Up a WIN Clinic within an Existing ANC:

- A senior midwife (or a small group of midwives) can be identified who has an interest in this area (or a willingness to be trained) and who already is familiar with the ANC.
- · A senior doctor working in ANC should also be identified who can receive complex cases for referral and review.
- Any woman identified at booking-in (ANC-1) who identifies as having a disability can be referred to the WIN clinic, which can operate on a particular day each week.
- Women with a disability generally need to be seen on a more regular basis than the normal antenatal care schedule- sometimes weekly, depending on their needs.
- The antenatal WIN clinic space should be accessible for women with mobility issues (for example, not only accessible by stairs), have appropriate equipment (such as an adjustable bed) and space for a support person who can assist with communication if necessary.
- The WIN midwife can see these women for longer appointments at each ANC visit to accommodate multiple needs.

- Care plans will be made in collaboration with the woman with a disability and other members of the health care team about her pregnancy, labour and childbirth and postnatal period, and clearly documented in the antenatal record for healthcare professionals to refer to.
- Encouraging support people to attend the clinic with the women during her pregnancy, giving them antenatal education and education about labour and birthing and support in the postnatal period.
- When the woman is admitted for birth, the WIN midwife can be notified (by either the woman herself or by health care staff) so that the WIN midwife can ensure appropriate resources are in place for a safe birth.
- The WIN midwife can visit the woman once she has delivered in the postnatal ward to check how the postnatal period is progressing, identify and manage any challenges and ensure the woman is ready to go home with the right supports in place.
- Follow-up can occur when the woman has been discharged by phone calls, or where possible, home visits.

⁵ https://www.thewomens.org.au/patients-visitors/clinics-and-services/pregnancy-birth/pregnancy-care-options/women-with-individual-needs

Best practice for clinicians working with pregnant women with disabilities

(Adapted from Smeltzer et al 2017)

SLIDE 28

1. Create an environment of mutual respect

 Women with a disability respect clinician's expertise and want to listen to suggestions. Understand the woman's individual experiences and how that can affect their perinatal health.

2. Ask questions

• If you are unfamiliar with a specific condition, ask the woman about it. Women with disabilities know their bodies best and are often knowledgeable about their conditions. When in doubt, ask the woman what works best for her.

3. Plan ahead

 Once you are aware of the specific conditions the woman has, do some research on the condition and its impact on pregnancy and childbirth. Consult early with other clinicians (such as obstetricians and anaesthetists) for planning for delivery.

4. Mothers with disabilities are women and mother's first

 Recognise and remove bias and judgement when working with women with disabilities. Women with disabilities want to raise children and give them the best life possible just like any other woman. Respect their autonomy and support their decision to have children.

In addition to the typical history performed at the first antenatal visit (commonly referred to as the "booking in" visit or ANC-1), the visit in the WIN clinic should include discussing the following:

- The woman's general health status
- The nature of the disabling condition
- Medications used to treat the disabling condition, or secondary conditions related to it. Some medications for specific disabilities are not safe in pregnancy and breastfeeding- eg some psychotropic medication and medication for treating epilepsy may need to be adjustedwomen should be referred for medical review
- The woman's concerns related to the interaction pregnancy has with her disabling condition
- Consideration that women with disabilities experience increased levels of physical and sexual abuse, clinicians should be alert to any disclosures of this nature and provide appropriate care (refer to GBV module)
- If a physical or gynaecological examination is required, time is taken to explain what is required and how it will be done - including how the woman will get onto the examination table, what position she can adopt, and that she is control of the examination. Consideration about her capacity for consent for a physical or gynaecological examination by considering her specific needs - such as having a support person with her so they can help with communication. Show her any instruments that will be used, such as a speculum and/or let her touch it if she wants to.
- Considerations for care for problems that may arise from physical disabilities in pregnancy (see Table 1 starting on page 15). Education based on the specific issue should be explained to the woman using language that she can understand.



Small Group Activity

SLIDE 29

Discuss in small groups the considerations for setting up a WIN clinic in your hospital. What would you need to do to set this up in the hospital you currently work in?

Table 1 - Care for Problems Arising from Physical Disabilities in Pregnancy

SLIDE 31-32

Problem	Disabling Conditions	Description	Implications For Care
Autonomic dysreflexia (autonomic reflexia)	Spinal cord injury, especially with lesions above T10 (and especially T6 and above)	Activation of the sympathetic nervous system can be triggered by uterine contractions, oxytocin, UTI, distension of the bladder, constipation, ectopic pregnancy, pelvic or rectal examination or pressure ulcers. Early signs and symptoms include headache, sweating and piloerection above the level of the spinal lesion nasal stuffiness and facial flushing. Severe symptoms include hypertension, irregular cardiac rate, shortness of breath and increased muscle spasticity. Severe complications include seizures, intracranial haemorrhage, coma and maternal death.	Women with spinal cord injury should be assessed for signs and factors that can precipitate autonomic reflexia such as full bladder or bowel, having a vaginal examination or being in labour. Vaginal examination should be performed when other staff are available to assist and with the woman's head elevated as high as possible. Rapid acting anti-hypertensives should be available and administered if required (such as Nifedipine IR). Emergency delivery may be indicated.
Deep vein thrombosis (DVT)	Disabilities that limit mobility e.g. wheelchair users	Venous stasis and pressure of the growing fetus prevent venous return from the legs therefore increasing risk of DVT.	Lower limbs should be assessed for warmth, redness, oedema or asymmetry. Elastic compression stockings and/or elevation of the lower extremities is useful, especially in late pregnancy.
Urinary tract infections (UTI)	Neurologic disorders e.g. spina bifida, spinal cord injury, cerebral palsy	Many physical disabilities increase risk of UTI- risk increases in pregnancy especially in women with neurogenic bladders. During pregnancy, infection is more likely to ascend to the kidneys and cause pyelonephritis, premature onset of labour and fetal mortality.	Increase fluid intake is recommended along with careful monitoring of urinary symptoms (including regular dipstick urine in the first instance) and prompt treatment with antibiotics when indicated.
Urinary incontinence	Neurologic disorders e.g. spina bifida, spinal cord injury, cerebral palsy	Urinary incontinence may increase in pregnancy in women with preexisting bladder dysfunction because of the pressure of the growing fetus.	A bladder management program should be implemented (this may include timed urination, in-out catheter or in-dwelling catheter).
Compromised respiratory function	Neurologic disorders e.g. high cervical or thoracic spinal cord injury, cystic fibrosis	The diaphragm is elevated and chest configuration is altered in the second half of pregnancy. Pre-existing respiratory dysfunction can worsen during late pregnancy and labour.	Respiratory function should be monitored. Availability for ventilatory support is essential if the woman is at high risk.

Problem	Disabling Conditions	Description	Implications For Care
Spasticity	Neurologic disorders e.g. spina bifida, spinal cord injury, cerebral palsy	Spasticity (increased muscle tone and resistance to passive movement) is often more pronounced at the extremes of range of motion. It is increased by pain, a cold room, contact with a cold speculum, stress and rapid movement.	Women with spasticity should be moved slowly and gently. Alternate positions for the pelvic examination may reduce risk of spasticity. To avoid falls, women who have spasms or spasticity should not be left alone on examination tables.
Risk of pressure ulcers	Neurologic disorders characterised by impaired sensation e.g. spinal cord injury	Pressure points may change during pregnancy as weight and body distribution change. Risk for pressure ulcers may be increased in women with anaemia.	Skin and bony prominences should be assessed frequently in women with impaired sensation. Women should be taught to assess their skin and change positions to prevent skin breakdown. Anaemia should be prevented through adequate iron intake.
Constipation	Neurologic disorders characterized by neurogenic bowel problems e.g. spinal cord injury	Supplemental iron may cause severe constipation during pregnancy in women with preexisting neurogenic bowel problems.	Nutritional modifications, increased fluid intake, cautious use of iron supplements, and stool softeners are indicated to prevent severe constipation.
Unrecognised onset of labour	Disabling conditions characterised by impaired sensation e.g. spinal cord injury, spina bifida	Unrecognized onset of labour may result in premature or unassisted delivery, increasing risks to baby and mother.	Women should be instructed to perform abdominal palpation and report changes that may indicate contractions. Women with spasticity may be more aware of the onset of contractions because of increased spasms and spasticity.
Severe fatigue	Disabling conditions such as rheumatoid arthritis and lupus	The fatigue common in pregnancy may be increased in women whose disabling conditions have fatigue as a major characteristic.	Fatigue may be especially severed during the first trimester. If it is incapacitating, women should be evaluated for treatable causes. Women can be advised to take scheduled rest periods during pregnancy and the postpartum period, use energy-saving strategies, and balance rest with exercise within the limits of their disabilities.
Falls	Conditions with impaired balance or coordination, muscle weakness, or paralysis e.g. spinal cord injury, spina bifida, cerebral palsy, amputated limbs	Change of the woman's centre of gravity late in pregnancy due to expanding uterus combined with impaired balance and lack of coordination due to disability increase the risk for falls.	Women at risk for falls should be encouraged to use assistive devices (canes, walkers, or wheelchair) to prevent falls and fractures. Prosthetic limbs may not fit properly because of increased weight and swelling.

Considerations for Antenatal Care in the WIN Clinic

SLIDE 33-36

1. Using the Two-Way Communication Card (Northcott Innovation 2024):

This can be used to help the pregnant woman with an intellectual or learning disability reflect on the way they would like to receive information. This card is intended to be stapled to their antenatal clinic card so that all health care professionals are reminded of the pregnant woman's communication needs (see Figure 1 below).

FIGURE 1. THE TWO-WAY COMMUNICATION CARD





2. Physical Clinic Accessibility:

An adjustable examination table to assist the woman with a disability to safely transfer from a wheelchair and back is advisable. If the facility is unable to provide this, other options can be looked at, including a clean cloth on a clean floor, or a simply made structure that is lower to the ground. All women should be asked what assistance they require to get ready for the examination and to move to the table or floor. The woman rather than the clinical staff should direct the process of transferring or changing positions.

3. Physical and Gynaecological Examinations:

Many women with disabilities receive gynaecologic care less often than women without disabilities, therefore clinicians should not assume that all women understand the purpose of routine examinations, vaginal/pelvic examinations particularly. If a woman has not had an examination in the past and is fearful, take time to build trust with her, be patient, ensure she has provided consent for you to perform the examination and allow her to guide the examination.

PERFORMING A PHYSICAL OR VAGINAL/PELVIC EXAMINATION:

When you examine a woman who is blind or cannot see well:

Offer your arm to her and let her rest her hand on yours - many blind women rely on their hands to "see" by touching. You can complete the physical examination like this, explaining what you are doing while you are doing it.

When you examine a woman who is deaf or cannot hear well:

Encourage deaf women to bring with her someone who can hear and knows her sign language and can interpret for her. If she has an interpreter, ensure that you look at the deaf woman while speaking, and look at her while she communicates to you.

When you examine a woman who has trouble understanding or learning:

A woman with an intellectual or learning disability should still get information about their health and be supported to make their own decisions. Ensure that a support person is present for critical discussions or when consent for procedures is required. Take time to explain things and ask her to repeat back to you in her own words so you can ensure she has understood and can consent to the examination.

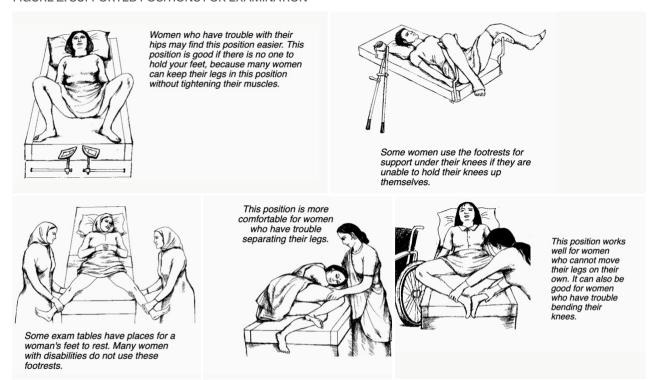
When you examine someone who cannot move their legs well (such as women with a physical disability such as a spinal cord injury):

Help her into a position that is comfortable and supported, ensuring you are alert to the risk of autonomic dysreflexia. If an internal examination is required and the woman has difficulty moving her legs, there are many different supported positions that can be used (see Figure 2). It is important to ask her what she is sensing throughout the examination and not assume she cannot feel anything. Even if the woman has no sensation to touch or pain, it is important to treat her with the same gentle touch and consideration that would be applied to any other woman.

When you examine someone who is experiencing a mental health issue (such as increased anxiety and/or agitation):

Assess whether the examination is critical at that time and could be delayed. If appropriate, assist the woman to how to do deep slow breathing and ensure that you give her time to see if she can calm herself and consent for the examination.

FIGURE 2. SUPPORTED POSITIONS FOR EXAMINATION



(Hesperin Health Guides, revised 2023)

4. Monitoring:

Other monitoring that is part of routine obstetric care may also require modification. This might include consideration of how to weigh and measure women who are wheelchair users and women who wear a prosthetic limb.

5. Collecting a Urine Specimen:

Some women may have difficulties providing a urine specimen because of physical limitations or because of limited spaces in antenatal clinics. Some women may need to perform self-catheterisation if they do this routinely, otherwise some women may require catheterisation to obtain a specimen. Another option is to provide the woman with a sterile container and ask her to bring it at her next appointment - she may be more able to collect a specimen at her home. The incidence of urinary tract infections (UTIs) is increased in women with disabilities during pregnancy, especially in women with neurogenic bladders associated with neurologic and musculoskeletal disorders. Untreated UTIs may precipitate autonomic dysreflexia in women with a spinal cord injury and may result in uterine contractions early in pregnancy. Therefore, frequent monitoring for UTIs is recommended - performing a dipstick urinalysis at every antenatal appointment is recommended (Smeltzer 2007).

Case Study: Meet Lola

SLIDE 37-40

You are the WIN midwife in a busy maternity hospital. You run a WIN clinic on a Wednesday, and all pregnant women with a disability are referred to you after their first booking in visit. An antenatal clinic midwife has referred Lola to you, after identifying a disability at her first booking in visit.

Lola is a 27-year-old woman who has cerebral palsy - she has an intellectual disability and a spinal deformity and uses crutches to walk. Lola is now 6 months pregnant and arrives to the WIN clinic for her first visit, accompanied by her mother.



Ask workshop participants - What do you need to know to care for Lola?

(Answers you would expect from your workshop participants in italics below)

- · A health history including a physical examination identifying what Lola's physical limitations are. Because of her spinal deformity and limitations in the movements of her legs, she may have difficulty getting onto the examination bed and positioning her legs.
- · How best Lola can understand information related to her pregnancy- filling out the "two-way communication card".
- · Are there any concerns about sexual abuse or gender-based violence voiced by Lola or her mother?
- Does Lola have emotional and physical support from her mother who is her caregiver?

From the health history and physical examination you find out that:

- · Lola has a very supportive mother who plans for Lola to stay with her and she will take care of Lola and the baby while maintaining her work during the day outside the home.
- · Lola has a boyfriend who is the father of the baby, but he has an intellectual disability and will not be involved in the care of the baby.
- · Sexual or physical abuse was not divulged- this was Lola and her boyfriend's first sexual experience, they like each other a lot but did not understand that sexual intercourse can result in a pregnancy.
- · Lola's physical limitations include some limited physical movement of her legs, but she managers very well with crutches and can transfer to a bed with minimal support at the moment.
- · She sometimes experiences leg cramping which she finds very painful but her and her mother don't know how to manage that.
- · You discover that Lola has limited capacity to understand medical terms and that you need to speak slowly and in simple language to ensure she understands the questions you ask of her. Her mother is able to use language that Lola understands to help.



Ask workshop participants - What are your concerns at this stage?

(Answers you would expect from your workshop participants in italics below)

- Mobility related to increasing size of uterus as pregnancy progresses and the risk of falls with walking and also transferring to chairs and beds
- · Does Lola's spinal deformity affect her pelvis and are there any concerns about the shape of her pelvis? She may require referral to an obstetrician to assist in a plan for birth if there are concerns about pelvic malformation
- Increased spasticity of Lola's leg muscles as the pregnancy progresses
- Lola's capacity to understand information about her pregnancy
- · Lola's ability to access the WIN clinic, delivery ward and other health facilities due to her reliance on crutches. Is Lola able to navigate stairs?

Ask workshop participants - What are your priorities?

- · Ensuring Lola and her mother understand the issues that may present to Lola during the next few months and how to manage them.
- Making a plan for what Lola will need during her labour and birth.
- Starting to make plans for what she will need to care for her baby at home.

Ask workshop participants - Identify strengths and possible threats to Lola?

- A supportive mother who is willing and able to help
- Her mother will be with her overnight but will be at work during the day
- · Her mobility as the pregnancy progresses and the weight of the uterus impacting upon balance that may increase the risk of falls.

Ask workshop participants - What is your plan for Lola to care for her during her pregnancy?

- · Because she is now 6 months pregnant, you would like to see her every week at the WIN clinic for closer monitoring.
- Referral to an obstetrician to assess her pelvis.
- Ensure the two-way communication card is filled out and stapled to her antenatal clinic card.
- Ensure Lola and her mother know the ways to decrease risk of falls as her pregnancy progresses assess how she uses crutches, ensure use of crutches all the time, especially when Lola is on her own.
- Ensure a discussion about family planning is commenced with Lola before she is discharged from hospital so that she has time to understand and consider her contraceptive options.

END OF MODULE 2 ►

Module 3

Labour and Birth





SLIDE 43

Like all women, women with a disability are often anxious and concerned about labour and birth, but additional specific concerns can arise related to the nature of specific disabilities. Women have reported that a decision about the type of birth they could have (often an elective caesarean) was often made arbitrarily, without consulting them or considering the possibility of vaginal birth (Nguyen et al 2022).

A systematic review has shown that overall, women with any type of disability are about 30% more likely to have a caesarean section than those without a disability (Tarasoff et al. 2020).

There are circumstances in which caesarean birth is needed for the safety and well-being of the mother and baby, but concerns have been raised about unnecessary caesarean sections among women with disabilities (Biel et al. 2020). The decision for caesarean section should be based on sound obstetric indications, rather than merely the presence of a disability. Women are often able to identify what they will and will not be able to do during labour and birth. For example, if a woman with a physical disability is able to generate adequate abdominal pressure for effective bowel and urinary elimination, she is more likely to be able to actively and effective push (bear down) during second stage labour (Tarasoff et al. 2020).

Considerations for Labour and Birth Care

SLIDE 44-49

1. Support Person

Giving birth for a woman with a disability will be easier if she has a support person (birth companion) of her choice with her during her labour and birth. This support person can help her to understand what is going on and provide physical and emotional support.

2. Ensuring the Woman's Bladder Remains Empty

For women with a spinal cord injury, the risk of dysreflexia from a full bladder is significant. An indwelling catheter can be placed during labour to prevent dysreflexia; ensure that the catheter does not become twisted or displaced so that urine can freely drain. For women with restricted mobility, the accessibility of bathrooms in the labour ward must be considered. Women with mobility challenges may require additional support to empty their bladder during labour.

3. Use of Upright Positions for Labour and Birth

Support the woman to choose the position she would like to be in and that feels most comfortable to her - she does not need to remain in bed if she has the right supports around her. Several positions depicted in Figure 3 (page 22) have been well utilised by women with physical disabilities even where she has limited arm or leg control.

FIGURE 3. POSITIONS FOR LABOUR AND BIRTH AND FAUTUMA'S STORY





Or you can rest on cushions in a halfsitting position.



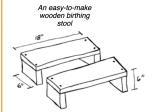
If you have little or no leg control, you can lie on your side while someone holds your top leg, with your legs



Fatuma's birthing stool

Fatuma Achan lives in Uganda and is paralyzed in both legs from having had polio as a child. When Fatuma became pregnant, like most disabled women, she was told by the doctors at the local clinic she had to give birth by an operation (a Cesarean section, or c-section)

Fatuma was determined not to have an operation but to go through normal labor. Other women in her community sometimes gave birth by squatting. Because her legs were paralyzed, Fatuma knew that she would not be able to hold herself in the squatting position. But she also knew her arms were very strong from pushing her wheelchair all the time. So she built a birthing stool which enabled her to stay in the squatting position. This way her baby could still be born through the vagina.





Even though Fatuma is paralyzed, her womb is still strong and can squeeze itself (contract) to push out a baby. The position of her body on the birthing stool helps the baby drop down gently out of her body through the vagina, just as it does for other women who squat during



If you have some leg and arm control, you may want to try the hands-and-knees position. This position sometimes also helps prevent and control muscle spasms.

(Hesperin Health Guides, revised 2023)

4. Management of Muscle Cramping

Women with cerebral palsy, a spinal cord injury, or who are paralysed from polio can get muscle cramps or tight spastic muscles at any time during labour and birth. Pulling or pushing directly against the spastic muscle will cause it to tighten more. Figure 4 shows some ideas for softening spastic muscles during labour.

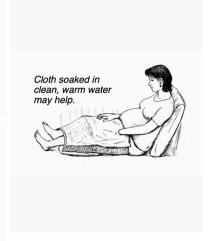
FIGURE 4. POSITIONS TO HELP WITH MUSCLE CRAMPING



Throughout labor, do range-of-motion exercises between contractions. If necessary, have someone help. The exercises will keep muscles loose and help prevent cramps and spasms.



Do not try to pull a woman's legs apart at the ankles. This will make her legs pull together more tightly. Instead, after lifting her head and shoulders, bend her legs. To separate her legs, first bring the knees together. This may unlock the legs. If not. hold the legs above the knees and they will open more easily.



(Hesperin Health Guides, revised 2023)

5. Close Monitoring for Signs of Obstructed Labour

All women should be monitored for signs of obstructed labour. However, it is extremely important that women with spinal deformities be monitored very closely for signs their labour could be obstructing. Active labour should be diagnosed and thereafter vaginal examinations every 4 hours to check adequate dilation, adequate descent of fetal head and position of the fetus. Close attention to signs such as increasing body temperature and blood stained urine should alert clinicians to labour obstructing with appropriate referral to medical staff and higher level facilities if needed.

Case Study: Lola's Labour and Birth

SLIDE 50

Lola has seen the WIN midwife every week throughout her pregnancy and everything has progressed well. Lola experienced increased severe muscle spasticity and cramping in her legs towards the end of her pregnancy, which has been managed with warm cloths on her legs, and her mother has been helping her with range of movement exercises. Lola saw an experienced obstetrician during her pregnancy, and she was confident that Lola's pelvis was not impacted by her disability and a vaginal birth was possible.

Lola and her mother present to the labour ward at 0800 on a Thursday morning. The midwife-incharge identifies that Lola is in the WIN clinic and calls you as the WIN midwife to let you know she is in labour.

You arrive at the labour ward to find Lola contracting well. She has not yet had an internal examination and you speak to the midwife caring for Lola.



Ask workshop participants - What is your plan of care at this time for Lola to ensure that she has a safe labour and birth?

(Answers you would expect from your workshop participants in italics below)

- Ensure Lola's mother is welcomed into the labour room to assist in caring for Lola so she can assist Lola understand what is being done and assist her physically.
- · Ensure the labour ward staff have seen the two-way communication card and they understand how to best communicate with Lola.
- · Assist Lola into a position for a vaginal examination after obtaining informed consent and discussing the need for the internal examination - because of the increased cramping she has been experiencing, time to gently assist her into position without forcing her muscles is required.
- · Once active labour has begun, ensure regular 4 hour vaginal examinations are undertaken to assess adequate progress of labour (dilatation, descent and position of baby) and ensure regular monitoring for signs of obstructed labour.
- · Remind Lola and the staff caring for her of the upright positions she can use for her labour to help manage her labour pains.
- Mobility support to use the bathroom and empty her bladder
- Plan to visit Lola in the postnatal ward after birth.

END OF MODULE 3 •

Module 4

Postnatal Care and Family Planning





Postnatal Care

SLIDE 54-58

Women with disabilities may require a longer period of time in the postnatal ward to recover from vaginal birth or caesarean section, either physically, emotionally or both. The needs of women following delivery will vary based on the changes that have occurred during pregnancy and their risk of increased symptoms or disability during the postpartum period. For example, some cell-mediated immune disorders like rheumatoid arthritis and multiple sclerosis can flare during the postpartum period, while other immune disorders like lupus may worsen during pregnancy (Smeltzer et al. 2017).

Considerations for care in the postpartum period:

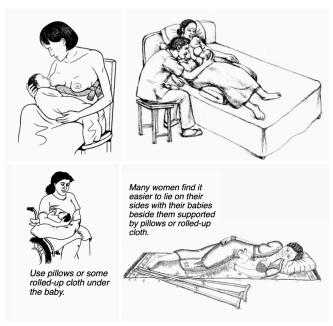
- · Accessibility for mobility aids, modification of the bathrooms and hospital rooms (which may need to include space for a support person).
- Women whose medication was halted during pregnancy may need to resume therapy soon after delivery to prevent symptoms and increased disability. Some medications are contraindicated for breastfeeding; women will need to be supported and counselled on the best method of feeding their baby available
- An appropriate length of stay, not only to ensure any medical issues are followed up, but also time for the mother to become comfortable with caring for her baby and for her support people to learn what assistance she needs.

- Many women continue to experience negative responses because of bias and stereotyping related to beliefs around a woman with a disability's capacity to parent-the WIN midwife who can identify resources and support early mothercrafting can be really helpful for the woman and her support people in the early days of parenting.
- The provision of a bed close to the floor for a woman who has mobility issues.
- Close access to the baby a simple crib can be made from a wooden box with an opening on the side (see Figure 5), which can allow the woman to have easy and safe access to her baby, and will also help if she cannot hear or see the baby, or has mobility issues.
- Breastfeeding support Women with disabilities that affect their upper extremities may initially require assistance and guidance to identify positions and adaptive strategies that allow them to hold the baby to the breast comfortably and safely (see Figure 6).
- Other resources for home should be identified, and time to procure them or have them made prior to discharge should be in place, such as changing tables close to the ground or baby carriers/slings if a woman used crutches (see Figure 7).

FIGURE 5. SAFELY KEEPING A BABY CLOSE TO YOU IN BED

(Hesperin Health Guides, revised 2023)

FIGURE 6. POSITIONS TO ASSIST BREASTFEEDING



(Hesperin Health Guides, revised 2023)

FIGURE 7. SAFE WAYS OF CARRYING A BABY



(Hesperin Health Guides, revised 2023)

Family Planning

SLIDE 59-60

All women, including those with a disability, have the right to make informed decisions about family planning, including the use of contraception and which method of contraception they use. Women with an intellectual disability face the same issues of fertility and menstrual management as other women. However, issues of informed consent are more complex for women with a disability these women need to be provided with accessible and accurate information, and any additional supports put in place to assist them in making their own informed decisions (RANZCOG 2021). Consideration must be given to women with disabilities, particularly those with intellectual disabilities, who have historically and continue to be subjected to involuntary contraception, abortion and sterilisation. These procedures are often undertaken without appropriate informed consent, under coercion, or even without the woman's knowledge, which is a violation of human rights (WHO 2022).

Considerations for provision of family planning:

- Long-acting reversible contraceptive implants, for example the implant (e.g. Jadelle) or an Intrauterine Device (e.g. hormonal or Copper-T IUD) should be considered in preference to irreversible surgical options.
- Time should be taken to ensure the woman understands all available options, and is supported to make her own informed decisions. Women with a serious impairment to mental function may still be able to participate in decisions affecting their reproduction.
- Never presume that a woman with a disability will not want more children in the future, but safe birth spacing should be discussed for health benefits and also to address the issues associated with her pregnancy and disability before she becomes pregnant again

Case Study: Visiting Lola in the postnatal ward

SLIDE 61

As the WIN midwife, you visit Lola in the postnatal ward the next day. Lola gave birth to a baby boy by normal vaginal birth. She lost 400 mLs of blood at delivery and has some perineal sutures for a 2nd degree perineal tear.

Lola is now on the postnatal ward and her is mother is able to stay with her to assist. She is trying to breastfeed but is having some difficulty attaching her baby to the breast. She is also having trouble comforting the baby when he is crying, as she cannot walk with her crutches and hold her baby at the same time.



Ask workshop participants - What is your plan of care for Lola in the postnatal ward before she can go home?

(Answers you would expect from your workshop participants in italics below)

- · Assisting Lola with different positions for breastfeeding to improve attachment of her baby at the breast.
- · Showing Lola and her mother how to use a baby carrier or sling so her baby can be safely carried by Lola while she is walking with her crutches. (See Figure 7 page 25)
- · Ensuring the right equipment or structures are ready at home to assist in Lola safely caring for her baby (such as an appropriate baby cradle, or a baby changing table at an appropriate height).
- Ensuring Lola is comfortable and able to respond to her baby's needs before she is discharged.
- · Conducting an assessment of her physical symptoms and management plan.
- A discussion and plan for postpartum contraception before she leaves hospital.

FND OF MODULF 4 •

Conclusion

SLIDE 64

The number of women with disabilities is increasing worldwide, and many have the same desires as other women to become parents. Negative attitudes and biases, inadequate knowledge about their healthcare needs, and lack of attention to the issues and concerns of women with disabilities have made the process difficult for many women. With the right support and positive attitude towards these women's pregnancies, midwives can provide care to these women that will improve outcomes for them, their babies, families and communities.



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WHO disability-inclusive health services training package. Manila: World Health Organization regional Office for the Western Pacific; 2022. licence: CC BY-NC-sA 3.0 IgO.

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