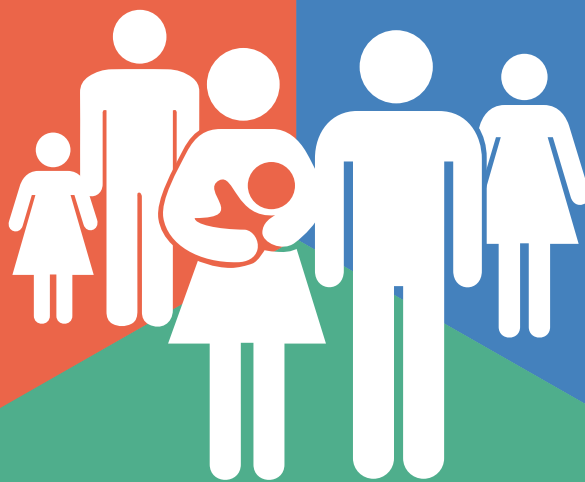


WHO TOOLKIT

FOR THE CARE AND SUPPORT OF PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS



**World Health
Organization**

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Preface

Zika virus (ZIKV) is associated with severe neurological complications, particularly congenital Zika virus syndrome (CZVS) and Guillain Barré syndrome (GBS). As cases continue to emerge from around the world, it is apparent that there is a great need to build capacity and strengthen health systems to enhance detection of complications which may have long-term implications, as well as provide the necessary care and programmatic support in affected countries and regions.

While primary infection by ZIKV is relatively mild, the associated complications have a marked impact on the people affected and their communities, including both physical and mental health. A strategy for long-term response is needed, as the associated complications will impact communities for generations.

In order to provide the tools to effectively recognize people affected by ZIKV and offer comprehensive care and support, the WHO Toolkit for the care and support of people affected by complications associated with Zika virus has been developed. The toolkit is intended to provide a systems approach involving public health planners and managers so that the necessary infrastructure and resources can be identified and incorporated as needed, as well as technical and practical guidance for health care professionals and community workers.

Overview

WHO Toolkit for the care and support of people affected by complications associated with Zika virus

This toolkit incorporates and builds upon the relevant guidelines and supportive documents developed in the past year from WHO and partners as part of the overall global response to ZIKV. The toolkit is designed to serve as a model guide, with the goal of enhancing country preparedness for ZIKV outbreaks. It is essential that the toolkit be adapted to the unique national or local context before implementation.

Although first identified in the mid-20th century, knowledge about the impact of ZIKV has rapidly grown in the past year due to recognition of the impact of the virus on the developing fetus. Despite the relatively large body of evidence that has emerged as a result, knowledge about the virus, impact, and long-term consequences is constantly evolving. Therefore, it is essential that the information provided in these manuals be frequently re-evaluated to provide the most accurate evidence-based guidance. The current manuals will be reviewed by June 2018 for this purpose.



Manual for public health planners and managers

MODULE 1:
Essential information on complications associated with Zika virus

MODULE 2:
Strengthening the long-term response to Zika virus



Manual for health care professionals

MODULE 1: Management of children born in Zika virus-affected areas

MODULE 2: Assessment and management of people with Guillain Barré syndrome and other neurological complications triggered by Zika virus

MODULE 3: Mental health and psychosocial support for people affected by complications associated with Zika virus



Manual for community workers

MODULE 1: Providing care and support for children in a Zika virus-affected area

MODULE 2: Psychosocial support for caregivers and families of children with or at risk for congenital Zika virus syndrome

MODULE 3: Rehabilitation and psychosocial support for people affected by Guillain Barré syndrome triggered by Zika virus







Introduction

Zika virus and associated complications

The history of Zika virus (ZIKV) outbreaks

ZIKV has been reported in humans since 1952 (first in Uganda and Tanzania); however, as the primary infection symptoms were mild, the virus was relatively unknown until larger outbreaks. The first large outbreak was in 2007, from the Island of Yap (Federated States of Micronesia), followed by French Polynesia in 2013. In 2015, ZIKV gained global attention when Brazil reported a large outbreak and a concerning increase of both microcephaly, a condition where a baby is born with a small head or the head stops growing after birth, and possible association with GBS, an acute neuropathy that affects the nerves controlling muscle strength, transmitting pain, temperature, and touch sensations.

What is ZIKV infection

ZIKV infection in an otherwise healthy person is typically asymptomatic, and for those who do experience them, the symptoms tend to be mild. Symptoms last 2-7 days and consist of a combination of fever, skin rash, conjunctivitis, muscle and joint pain, malaise and headache.

How ZIKV is transmitted and who is at risk

Transmission of ZIKV is primarily through the Aedes mosquitos (*Aedes aegypti*). The mosquito mainly bites during the day, with peak times in the early morning and late afternoon or early evening. It is the same mosquito that transmits dengue, chikungunya, and yellow fever. ZIKV can be transmitted sexually and there is also concern for transmission via blood transfusion.

Anyone can get ZIKV. The risk of primary infection in pregnant women is the same as other adults. However, there is significant risk is to the unborn child, who is at risk of developing the severe complication of congenital Zika virus syndrome (CZVS) if infection occurs during pregnancy.

How to reduce and prevent transmission of ZIKV

Protection against mosquito bites is the best method for prevention of ZIKV transmission and its spread. General recommendations include: wearing clothes which cover as much of the body as possible, using insect repellent (DEET, IR3535, or icaridin), and protecting areas of residence with mosquito nets, window screens, and covering, emptying, or cleaning potential breeding sites for mosquitos.

WHO recommends the following to decrease the risk by sexual transmission:

- In ZIKV affected areas, pregnant women and their partners should practice safe sex or abstain from sexual activity for at least the entire duration of the pregnancy. In these regions, counselling and a full range of contraceptive methods should be made available so that sexually active men and women can make an informed choice about whether and when to become pregnant.
- For men and women returning from areas where transmission of ZIKV is known to occur, it is recommended that safer sex practices or abstinence be adopted for at least six months upon return to prevent transmission (sexual partners of pregnant woman should follow for whole duration of pregnancy).
- Couples or women returning from a ZIKV affected area who are planning a pregnancy should wait six months before trying to conceive.

Due to the suspected risk of ZIKV through blood transfusion, WHO recommends that there is a temporary exclusion of donors (for at least 28 days) with a recent clinical history consistent with ZIKV, laboratory evidence of ZIKV, and history of sexual intercourse with men with confirmed or suspected ZIKV in prior three months.

How to diagnose ZIKV

Diagnosis of ZIKV should be suspected based upon symptoms and exposure (residence or travel to an area with active ZIKV transmission) or sexual contact with a person who has been exposed to a region of risk.

Diagnosis can only be confirmed through laboratory tests. ZIKV has been detected in blood, urine, saliva, cerebrospinal fluid (CSF), semen, and amniotic fluid as well as tissue samples. WHO recommends testing blood and urine for ZIKV, and if available, CSF. Routine testing of semen is not recommended.

- RT-PCR should be performed on blood and/or urine collected from patients presenting with an onset of symptoms ≤ 7 days.
- IgM antibody testing should be performed on blood from patients presenting with onset of symptoms ≥ 7 days.
- If available, RT-PCR or IgM antibody testing can be performed on CSF.
- Whenever possible, paired serum specimens should be collected at least 2-3 weeks apart, ideally with the first serum specimen collected during the first 5 days of illness.
- ZIKV should be tested in addition to dengue and chikungunya either sequentially or in parallel, with consideration for endemic circulation of other flaviviruses.

Reporting of ZIKV cases should be done in accordance with the regional health authority and per WHO International Health Regulations (IHR) guidance.

Complications associated with ZIKV

Based upon a systematic review of the literature up to 30 May 2016, WHO concluded that ZIKV infection during pregnancy is a cause of congenital brain abnormalities, including microcephaly; and that ZIKV is a trigger of Guillain Barré syndrome. Since that time, further evidence supporting a causal link between the virus and these complications has been found (Krauer et al., 2017). There is also concern of ZIKV being linked to other neurological complications, including meningitis, meningoencephalitis, and acute myelitis.

Congenital Zika virus syndrome (CZVS) refers to a constellation of neurodevelopmental signs and symptoms associated with a congenital ZIKV infection, that may manifest at any point in infancy or during the prenatal period. This includes wide range of associated conditions including brain malformations, seizures, irritability, swallowing problems, limb contractures, hearing and sight abnormalities (WHO ZIKV screening assessment interim guidance, 2016). It is important to recognize that not all exposed pregnant women will have a child with CZVS. While evidence suggests a significant risk to the unborn child with ZIKV infection at any stage of pregnancy, exact risk is unknown.

Guillain Barré syndrome (GBS) is an acute immune-mediated neuropathy that affects the nerves controlling muscle strength and nerves transmitting pain, temperature, and touch sensations. It has the potential to be life threatening as up to 20-30% of affected people develop respiratory failure and there is a 5% mortality rate even with optimal care. GBS occurring at high incidence rates (up to 20-fold increase in baseline rate) in ZIKV-affected areas and both adults and children have been affected. Even with optimal treatment, GBS is a significant cause of long-term disability and rehabilitation is required (short-term and long-term). Physical rehabilitation, nutritional and psychosocial support for individuals with GBS is essential to treatment.

Psychosocial needs

Pregnant women (and partners) in ZIKV affected areas may face fear and distress about their pregnancy. Misconceptions about the virus may contribute to such reactions. There is also a significant difference in emotional and psychosocial wellbeing in parents of children with disabilities in comparison to families without a child with disability and it is important to provide appropriate mental health and psychosocial support to these caregivers.

Persons affected by GBS are most commonly previously healthy, able bodied people who now have long roads of uncertain recovery ahead of them with significant emotional and financial stress as a result.

The stigma surrounding ZIKV is high, particularly in children affected by CZVS. Mothers of these children are, in particular, more isolated as a result. This may lead to other socioeconomic problems for parents and families, reducing their access to care and support and impacting on their livelihoods. Misconceptions about transmission, cause of the disability, and blaming of the parents may exist, thus compounding feelings of isolation, guilt, stress, and depression that may be felt by the family of the child and child as he/she gets older.

Stigma and discrimination in ZIKV

Stigma and discrimination represent two common barriers affecting people with disabilities and their families. Barriers are factors that limit functioning and create disability by their presence or absence, and range from inaccessible physical environments to negative attitudes toward people affected by a health condition such as ZIKV.

- In the knowledge, attitudes and practices survey conducted in New York City, 25.3% of the participants indicated that an individual who develops ZIKV will face stigma. 32.0% indicated that if a woman has a child with microcephaly or other disability, she would be stigmatized.

It is important to preserve the dignity of people facing stigma and discrimination. Dignity has two main dimensions: Self-worth as perceived by the individual and worth of the individual reflected in respectful attitudes and practices of others.

Stigma can negatively impact people affected by the complications associated with ZIKV. The impacts on the individual may include a perceived sense of discrimination, exclusion, stress and may lead to isolation of the person and families and avoiding access to services including educational and health care services.

The Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) provide countries with a framework for ensuring that children with disabilities including those with long-term mental, physical, intellectual or sensory impairment are protected and their rights are preserved without discrimination, emphasising the following key elements:

- remove barriers, such as stigma and discrimination, that impede the full inclusion of children with disabilities in communities, schools and families;
- develop community-based resources, such as inclusive schools, and health and rehabilitation;
- services that are available and accessible to all families, regardless of income level; and

- recognize that children are best cared for in family-centred environments that allow for the development of attachments that are critical for a child to reach his or her optimal development.

Essential rights of people affected by the complications associated with ZIKV include:

- the right to live, to receive equal education, health care to other children;
- the right to be part of the community and to be protected from any harmful abuse or exploitation; and placing a child with CZVS or other ZIKV related complications in an institution is a fundamental violation of human rights. It is the responsibility of governments to respect, protect and fulfil the human rights of its most marginalized and socially excluded people, including those affected by the complications associated with ZIKV.

Providers can promote an understanding of human rights, dignity and importance of community care through education and raising awareness in the community.

- Include education on dignity of people affected by ZIKV and its complication as a part of all training activities for health and community workers. Provide education about the complications associated with ZIKV in public places (e.g. schools, health care centres, etc.).
- Identify and address misconceptions on ZIKV in the community.
- Utilise the media to increase awareness of complications of ZIKV.
- Hold public events and lectures about of ZIKV and associated complications.
- Ensure that community has direct and positive social contact with people affected by ZIKV and its complications.
- Include and mobilize people affected by complications associated with ZIKV, including encouraging families and caregivers to participate in advocacy actions.

KEY MESSAGES

- ➔ *ZIKV is a typically asymptomatic or mild infection lasting 2-7 days in a healthy individual.*
- ➔ *ZIKV infection during pregnancy puts the fetus at risk of microcephaly and congenital brain anomalies.*
- ➔ *ZIKV can trigger the neurological complication of Guillain Barré syndrome in older children and adults.*
- ➔ *The best way to protect against the virus is to use protective clothing, insect repellent and mosquito nets.*
- ➔ *ZIKV can also be transmitted sexually and safe practices are recommended for individuals who have been exposed to the virus.*
- ➔ *It is highly suspected ZIKV can be transmitted through blood and precautions for safe blood supplies is recommended.*
- ➔ *There are significant psychosocial concerns surrounding ZIKV and the associated complications.*
- ➔ *Stigma and discrimination are two common barriers affecting people with disabilities.*
- ➔ *International Human Rights Instruments promote rights and dignity of children and adults with disabilities.*
- ➔ *Children with psychosocial disabilities have the right to be remain in and contribute to their communities and receive equal services to others.*

LINKS TO RELEVANT RESOURCES

General information about ZIKV: <http://www.who.int/mediacentre/factsheets/zika/en/>

Interim guidance about ZIKV: <http://www.who.int/csr/resources/publications/zika/laboratory-testing/en/>;
<http://www.who.int/csr/resources/publications/zika/surveillance/en/>; <http://www.who.int/csr/resources/publications/zika/sexual-transmission-prevention/en/>; <http://www.who.int/features/qa/zika-safe-blood/en/>; http://apps.who.int/iris/bitstream/10665/204475/1/WHO_ZIKV_MOC_16.3_eng.pdf?ua=1

Educational materials on risk communication and community engagement (RCCE) for ZIKV response:
<http://www.who.int/risk-communication/zika-virus/training/en/>; http://apps.who.int/iris/bitstream/10665/204513/1/WHO_ZIKV_RCCE_16.1_eng.pdf?ua=1; <http://www.who.int/csr/resources/publications/zika/community-engagement/en/>;
https://www.unicef.org/cbsc/files/Zika_Virus_Prevention_and_Control_UNICEF_English.pdf

Alert, response, and capacity building under the International Health Regulations (IHR):
<http://www.who.int/ihr/9789241596664/en/>

Knowledge, Attitudes and Practice surveys: Zika virus disease and potential complications
<http://www.who.int/csr/resources/publications/zika/kap-surveys/en/>

Convention on Rights of Children <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

Convention on Rights of Persons with Disabilities
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

Promoting rights and community living for children with psychosocial disabilities:
http://apps.who.int/iris/bitstream/10665/184033/1/9789241565004_eng.pdf

WHO International Health Regulations (IHR) guidance
http://www.who.int/topics/international_health_regulations/en/

Krauer F, Riesen M, Reveiz L, Oladapo OT, Martínez-Vega R, Porgo TV, et al. (2017) Zika Virus Infection as a Cause of Congenital Brain Abnormalities and Guillain–Barré Syndrome: Systematic Review. PLoS Med 14(1): e1002203. doi:10.1371/journal.pmed.1002203

**WHO TOOLKIT FOR THE CARE AND SUPPORT
OF PEOPLE AFFECTED BY COMPLICATIONS
ASSOCIATED WITH ZIKA VIRUS**

Manual for public health planners and managers



**World Health
Organization**





¿Qué es?

Es una enfermedad causada por el virus del mismo nombre, el cual se aisló por primera vez en los Bosques de Zika en Uganda, en el año 1947, en un mono Rhesus, durante un estudio de fiebre amarilla.

Aunque la infección en seres humanos se demostró por estudiosológicos realizados en 1952 en Uganda y Tanzania, solo hasta 1968 se pudo aislar el virus a partir de muestras humanas en Nigeria. El virus del Zika, pertenece a la familia Flaviviridae, muy cercano al virus del Dengue, la Fiebre Amarilla, la Encefalitis y el virus del Nilo Occidental.

Síntomas

- Los síntomas duran de dos a siete días.
- Fiebre, conjuntivitis no purulenta, dolor de cabeza, dolor en el cuerpo y articulaciones, prurito (rasquiña), rash (brote), edema (hinchazón) en extremidades inferiores.
- Con menor frecuencia se puede presentar: falta de apetito, vómito, diarrea y dolor abdominal.
- Las manifestaciones clínicas graves son muy poco frecuentes comprenden alteraciones del sistema neurológico e inmunológico.

Secretaría de Salud
Municipalidad de San José de Cúcuta



Zika ¿Cómo se transmite?

Por la picadura del mosquito *Aedes aegypti* o *Aedes albopictus* infectado, que es el mismo vector del dengue y chikunguña.

Para que sea efectiva la transmisión de la enfermedad, tienen que estar presentes en forma simultánea el virus, el vector y el huésped susceptible.

La enfermedad se manifiesta de tres a doce días después de la picadura por el vector infectado.

LA ENFERMEDAD NO SE TRANSMITE POR EL AIRE

This manual is designed for public health planners, including decision-makers in the health system, and managers who design and carry out public health programmes, to guide the continuing response to Zika virus, its complications and the consequences for countries and regions. The manual is intended to outline the main considerations in mainstreaming services for people affected by complications associated with Zika virus and the concrete steps to be taken to enhance care and support. Throughout the manual, lessons learnt, essential resources and indicators for monitoring are highlighted.

MODULE 1

Essential information on complications associated with Zika virus

- 1.1 *Introduction*
- 1.2 *Framework for enhancing care and support*
- 1.3 *Requirements for mainstreaming care and support into health care settings*
- 1.4 *Community empowerment*
- 1.5 *Collaboration*

MODULE 2

Strengthening the long-term response to Zika virus

- 2.1 *Establishing a stakeholder group*
- 2.2 *Situation analysis*
- 2.3 *Workforce capacity building*
- 2.4 *Surveillance*
- 2.5 *Research*

1

MODULE

Essential information on complications associated with Zika virus

This module provides an overview of the information required by public health planners and managers for enhancing care and support for people affected by complications associated with Zika virus:

- 1.1 Introduction*
- 1.2 Framework for enhancing care and support*
- 1.3 Requirements for mainstreaming care and support into health care settings*
- 1.4 Community empowerment*
- 1.5 Collaboration*



Introduction

The spread of Zika virus (ZIKV) and its associated complications represent a new public health challenge that requires a unique, integrated strategy (1). People affected by complications associated with ZIKV, including children born with or at risk for congenital ZIKV syndrome (CZVS) and individuals with Guillain Barré syndrome (GBS) and other neurological disorders have a broad range of needs. Public health planners and managers have an important role in enhancing care and support to ensure that children living with CZVS, people living with GBS and other neurological disorders, and caregivers and families achieve optimal functioning, quality of life and participation in their communities.

BOX 1. SOURCES OF UP-TO-DATE INFORMATION ABOUT ZIKA VIRUS

WHO Zika portal: <http://www.who.int/topics/zika/en/>

WHO virus disease: <http://www.who.int/csr/disease/zika/en/>

WHO disease outbreak news: <http://www.who.int/csr/don/en/>

WHO Regional Office for the Americas Zika epidemiological update:
http://www.paho.org/hq/index.php?option=com_content&id=11599&Itemid=41691

WHO Zika situation reports: <http://www.who.int/emergencies/zika-virus/situation-report/en/>

US Centers for Disease Control and Prevention communication toolkit:
<https://www.cdc.gov/zika/comm-resources/toolkits.html>

Role of the health system

Health systems promote optimal functioning and quality of life for people affected by complications associated with ZIKV. Health services must be adequately prepared to deal with a surge in potential cases of complications. This will entail (i) strengthening first points of care and expanding community health services; (ii) improving access to family planning, counselling and reproductive health services; (iii) improving rehabilitation services, social protection, mental health and psychosocial support; (iv) encouraging community engagement to address stigma and discrimination; and (v) building the capacity of health care professionals and community workers to meet the immediate and long-term needs of those affected.

Human resources

Health care professionals and community workers are essential for effective preparation of the response to the needs of people affected by complications associated with ZIKV. Immediately after a ZIKV outbreak, they ensure effective community engagement and education, detection and diagnosis of cases and equitable access to high-quality essential health services. The workforce implications of long-term care for disability in both children and adults should be considered in the medium to long term, so that the necessary services are readily available when and where they are needed. A range of capabilities is required of the health workforce so that health systems can effectively respond to the needs of affected people.

The estimated shortage of personnel in specialized health care who can meet the needs of people affected by complications associated with ZIKV worldwide is overwhelming, with an overall lack of specialists in disciplines such as rehabilitation, neurology, mental health, psychosocial support, paediatrics and ear and eye care. Creative solutions are required to build the necessary capacity of health care professionals and community workers, with consideration of task sharing when appropriate.

An intersectoral response

Health and social care systems, including community care structures, should urgently revise or develop intersectoral responses in order to provide mainstream care and support for children, adults and families affected by complications associated with ZIKV (1), while maintaining respect and their dignity. Children with complications due to maternal ZIKV infection should be supported in achieving their full potential by rehabilitation services, early stimulation, social assistance and protection, psychosocial support and specialized health care and education. People with GBS and other neurological disorders due to ZIKV infection will require acute care, rehabilitation, psychosocial support and specialized health care to make an optimal recovery. Family income may be reduced by the increased care needs of people affected by congenital malformations and neurological disorders due to ZIKV infection, and governments might consider providing special support to such families.

Many disciplines are involved in both the immediate and the long term to ensure effective delivery of essential health and social care. Care and support for people affected by complications associated with ZIKV should be provided by a competent, skilled health and social care workforce and should be integrated into existing health and social care systems as much as possible. Services might have to be reconfigured to ensure timely access to quality care as close as possible to affected households.

Purpose of the manual

This manual provides practical guidance for mainstreaming care and support for people affected by complications associated with ZIKV into existing health care services.

The target readership is public health planners and managers working at national and regional levels in government and in national and international nongovernmental organizations in all countries that have reported vector-borne ZIKV transmission and also in countries at risk for ZIKV transmission. Managers and stakeholders working in other sectors will also benefit from the information provided. (See section 2.1.)  **2.1**

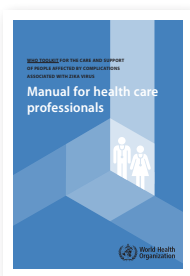
The topics discussed in the manual are listed in **Table 1**.

Cross-cutting principles

The cross-cutting principles¹ in **Table 2** form the foundation of the manual and should be the basis for any action to enhance care and support for people affected by complications associated with ZIKV.

EXPLORE THE WHO TOOLKIT FOR THE CARE AND SUPPORT OF PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH THE ZIKA VIRUS

For specific examples of the competencies that health care professionals and community workers can develop to provide care and support to people affected by complications associated with ZIKV, refer to:

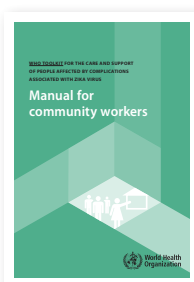


Manual for health care professionals

Module 1: Management of children born in Zika virus-affected areas

Module 2: Assessment and management of people with Guillain Barré syndrome and other neurological complications triggered by Zika virus

Module 3: Mental health and psychosocial support for people affected by complications associated with Zika virus



Manual for community workers

Module 1: Providing care and support for children in a Zika virus-affected area

Module 2: Psychosocial support for caregivers and families of children with or at risk of congenital Zika virus syndrome

Module 3: Rehabilitation and psychosocial support for people affected by Guillain Barré syndrome triggered by Zika virus

**TABLE 1. MANUAL FOR PUBLIC HEALTH PLANNERS AND MANAGERS
TOPICS, DESCRIPTIONS AND LEARNING OBJECTIVES**

No.	Topic and description	By the end of this section, public health planners and managers will be able to:
Module 1. Essential information on complications associated with Zika virus		
1.2	Framework for enhancing care and support: Enhanced care and support for such people is based on keeping them at the centre of all planning and implementation during collaboration with relevant sectors and disciplines. Consideration must be given to strengthening health and social care, community empowerment, surveillance and research.	<ul style="list-style-type: none"> • identify the key components of enhancing care and support for people affected by complications associated with ZIKV.
1.3	Requirements for mainstreaming care and support into health care settings: Consideration must be given to workforce competencies, equipment and resources in health care facilities and community level support.	<ul style="list-style-type: none"> • identify the resources necessary to mainstream care and support for people affected by complications associated with ZIKV.
1.4	Community empowerment: People affected by complications associated with ZIKV are supported in “having their voices heard” through advocacy, by mobilizing communities to create an inclusive environment and by promoting access to the same rights for all members of the community.	<ul style="list-style-type: none"> • promote self-advocacy by people affected by complications associated with ZIKV; • ensure that people affected by complications associated with ZIKV are properly represented in relevant bodies to ensure that their rights are protected; • support communities in creating inclusive environments; and • ensure that the role of community workers includes community empowerment.
1.5	Collaboration: Collaboration in multidisciplinary care and by engaging stakeholders (both within and outside of the health sector) to enhance care and support for people affected by complications associated with ZIKV, while promoting efficient use of resources	<ul style="list-style-type: none"> • identify the principles of multidisciplinary care; • identify and involve relevant stakeholders; and • establish appropriate networks or platforms or integrate ZIKV response into existing intersectoral platforms for planning and learning.
Module 2. Strengthening the long-term response to Zika virus		
2.1	Establishing a stakeholder group: A group that includes members from various ministries and departments relevant to complications associated with ZIKV, as well as other stakeholders, will facilitate planning and implementation of enhanced care and support for people affected by complications associated with ZIKV.	<ul style="list-style-type: none"> • identify potential members of the group and • establish the group.
2.2	Situation analysis: A comprehensive, multidisciplinary analysis of the context, including all levels of the health and social care systems, will form the basis for supporting people affected by complications associated with ZIKV.	<ul style="list-style-type: none"> • conduct a desk review to identify information and assessments conducted in ZIKV-affected areas; • collect information not found in the desk review; and • use the results of the situation analysis to identify short-, mid- and long-term priorities.
2.3	Workforce capacity building: Health care professionals and community workers must be trained and supervised to ensure the provision of comprehensive, high-quality services for people affected by complications associated with ZIKV.	<ul style="list-style-type: none"> • plan the roles of different actors in the health system, with task sharing to reduce strain on resource-poor services; • identify facilitators to train and supervise health care professionals and community workers; • identify health care professionals and community workers to participate in capacity building; • plan capacity building activities; and • consider long-term career paths and remuneration to sustain motivation and availability of personnel.

No.	Topic and description	By the end of this section, public health planners and managers will be able to:
2.4	Surveillance: Surveillance systems should be strengthened to include complications associated with ZIKV in order to understand the impact of ZIKV and to guide the country's health system response.	<ul style="list-style-type: none"> strengthen the surveillance system to monitor a range of birth defects and neurodevelopmental impairments and strengthen the surveillance system to monitor GBS and other neurological disorders.
2.5	Research: Evidence is required to prevent and limit the impact of ZIKV infection and its complications. Priorities for research and ethical considerations in ZIKV-affected areas should be identified.	<ul style="list-style-type: none"> identify priorities for research on complications associated with ZIKV; identify the ethical issues to be considered in conducting research in the context of ZIKV; coordinate appropriate participation in research, from biological to social and implementation sciences; and ensure that ethical guidance is in place and adhered to.

TABLE 2. CROSS-CUTTING PRINCIPLESⁱ

Human rights	Actions to enhance care and support for people affected by complications associated with ZIKV must be done with respect their inherent rights and comply with the Convention on the Rights of Persons with Disabilities, the Convention of the Rights of the Child and child-safeguarding standards. The empowerment and inclusion of community members affected by complications associated with ZIKV should be promoted at all times, including equal decision-making on care and services, without discrimination.
Gender	Policies, programmes and services for people affected by complications associated with ZIKV must be responsive to the specific needs of women, men, girls and boys, in all their diversity.
Quality of life	Actions to enhance care and support for people affected by complications associated with ZIKV should include promoting the quality of life of children and adults with short and long-term disabilities.
Life-course approach	Policies, plans and services for people affected by complications associated with ZIKV should include consideration of issues such as their stage of life – from pregnant women to infants with and at risk for birth defects, and also older children and adults with GBS and other neurological disorders.
Equity	Regardless of age, gender, socioeconomic status, race, ethnicity or sexual orientation and according to the principle of equity, people with complications associated with ZIKV should have access to essential health and social care services to enable them to achieve optimal functioning and the highest attainable standards of health and well-being.
Multisectoral approach	Comprehensive, coordinated care and support for people affected by complications associated with ZIKV require effective partnerships among multiple sectors.
Evidence-based policy and practice	Strategies and interventions for mainstreaming care and support for people affected by complications associated with ZIKV should be based on scientific evidence and/or best practice.
Cost-effectiveness	Care for people affected by complications associated with ZIKV should be integrated into health and social care systems rather than offered as segregated care. Task sharing can ensure rational optimization of the available health workforce.
Cultural acceptability	All recommendations on care and support for people affected by complications associated with ZIKV should be reviewed for cultural appropriateness and adapted to the local context and culture with the participation of local experts and the people using the services.

ⁱThe principles are integrated throughout the manual, in line with the Convention on the Rights of Persons with Disabilities, the Convention on the Rights of the Child, the Sustainable Development Goals, the Global Strategy for Women's, Children and Adolescents' Health and the Mental Health Action Plan.



Framework for enhancing care and support

The framework for enhancing care and support for people affected by complications associated with ZIKV places people at the centre of planning and action.

Four elements surround people affected by complications associated with ZIKV at the centre of framework: strengthening health and social care systems, community empowerment, surveillance and research. For these four elements to be effective, community members and other stakeholders must work collaboratively to optimize the functioning, quality of life and community participation of and with people affected by complications associated with ZIKV.

- **Strengthening health and social care systems:**

Health and social care systems should be strengthened to address the needs of people affected by complications associated with ZIKV. National and community systems should be strengthened to provide appropriate services and support to individuals, families and communities affected by the complications (1). Stakeholders (including governments, civil societies and nongovernmental organizations) can use the greater focus on the health of their population to “build back better” after an outbreak (**Box 2**) and strengthen their health and social care services to respond to the short- and long-term health implications and socio-economic consequences of ZIKV infection (2). **Annex 1** lists actions for system strengthening to support enhancement of care and support for people affected by complications associated with ZIKV.

- **Community empowerment:** Enhancing care and support for people affected by complications associated with ZIKV will be successful only if it is guided by the voices of the affected people. Communities that create inclusive environments create space for these voices to be heard. Empowering communities involves supporting and promoting opportunities for advocacy and inclusion of people affected by complications associated with ZIKV.

- **Surveillance:** Surveillance systems for complications associated with ZIKV should be developed, strengthened and used to provide up-to-date, accurate information to guide the care and support of people affected by complications associated with ZIKV.

- **Research:** Evidence is required to strengthen interventions to detect and prevent complications associated with ZIKV while developing innovative solutions to promote optimal outcomes and quality of life.

BOX 2. “BUILDING BACK BETTER”

This approach is often used in the recovery phase of an emergency or during a protracted emergency, in which the situation is used to strengthen health and social care systems.

WHO (2) identified the following commonalities and success factors from 10 case studies in which opportunities were seized to ensure better care both during and after emergencies.

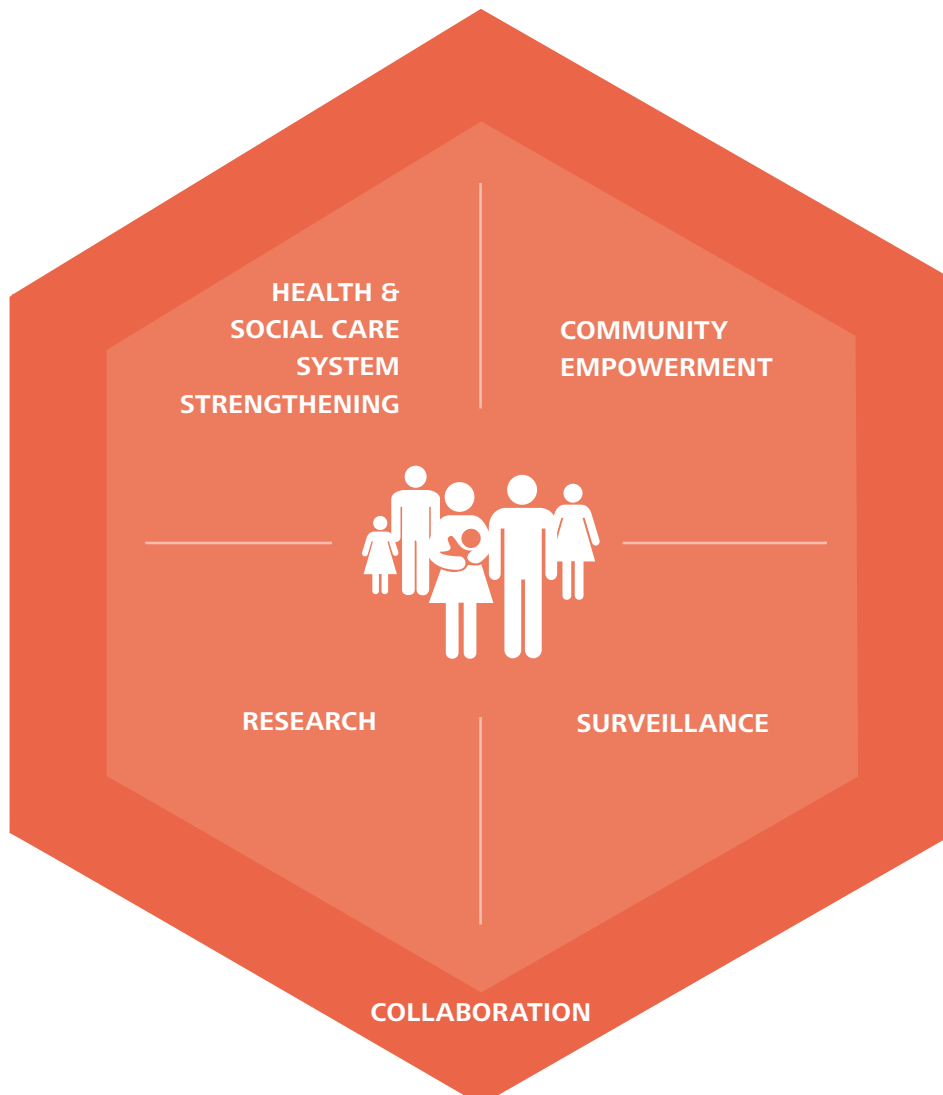
1. **Long-term planning:** Health and social care were supported by planning for long-term sustainability from the outset.
2. **Horizontal design:** The broad health and social needs of the population affected by the emergency were addressed.
3. **Government oversight:** The government’s central role was respected.
4. **Local champions:** National professionals played a key role.
5. **Coordination:** Coordination among agencies and sectors was crucial.
6. **Policy change:** Health and social care reform involved review and revision of national policies and plans.
7. **System-wide:** The health and social care systems were considered and strengthened as a whole.
8. **Capacity building:** Health care professionals were reorganized and trained.
9. **Evidence-based:** Demonstration projects offered proof of the concept and attracted further support and funds for enhancing health and social care systems.
10. **Advocacy:** Advocacy helped maintain the momentum for change.

The concept of **collaboration** is integrated into all the elements of the framework. The complications associated with ZIKV and the corresponding social implications are broad and therefore cannot be addressed by a sole sector or discipline. Enhancing care and support for people affected by such complications must include inter- and intrasectoral collaboration between and within disciplines, sectors, government ministries, communities and other stakeholders. Interventions

for long-term care and support should be integrated into existing health and social care systems rather than provided separately, as far as possible. All collaboration must include the affected people and their representative organizations.

The framework for enhancing care and support for people affected by complications associated with Zika virus is illustrated in **Fig. 1**.


FIG 1. FRAMEWORK FOR ENHANCING CARE AND SUPPORT FOR PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS





Requirements for mainstreaming care and support into health care settings

Table 3 lists the resources required to mainstream care and support for people affected by complications associated with ZIKV into an existing health system, according to the population addressed: women and girls of childbearing age, children with or at risk for CZVS and people with GBS and other neurological complications.

For specific examples of the competencies that health care professionals and community workers can develop to provide care and support to people affected by complications associated with ZIKV, refer to manuals for health care professionals and community workers. 

The resources required are presented in three categories: workforce competencies (skills required), equipment and resources in health facilities at different levels (such as diagnostic equipment and medications) and support in the community.

Services that can be provided by general health care professionals by task sharing are highlighted. It is recommended

that services that cannot be provided by general health care professionals be accessed by referral. In the Table, the term “facility” is used to indicate the point of entry of the population to health care.

Suggestions are made about making the resources available either directly within a facility or in referral facilities. For more guidance on referral systems, see **Box 3**.

TABLE 3. REQUIREMENTS FOR MAINSTREAMING CARE AND SUPPORT FOR PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKVⁱⁱ

3A. WOMEN AND GIRLS OF CHILDBEARING AGE

<p>Workforce competencies</p>	<ul style="list-style-type: none"> • All health care professionals are trained: <ul style="list-style-type: none"> • to provide appropriate counselling on ZIKV infection and associated risks and • to advocate for the needs of women and girls of childbearing age who are affected or at risk. • Each facility has access to health care professionals trained to provide routine antenatal care, including access to the safe reproductive choices available per local law. • All health care professionals are trained in supportive communication, basic psychosocial interventions and psychological first aid. • At least one health care professional in every facility is trained to provide services for mental disorders, including for perinatal depression. • At least one health care professional in every facility has a cooperating relationship with peer support group(s) and community-based resources and services.
<p>Equipment and resources placed in facilities</p>	<ul style="list-style-type: none"> • Each facility has access to: <ul style="list-style-type: none"> • fetal ultrasound capacity and • laboratories and additional diagnostic testing for ZIKV infection and STORCH infections. • Every facility has: <ul style="list-style-type: none"> • at least one safe, private location for a confidential psychosocial support session or clinical physical examination; and • access to at least one type of psychotropic medication in each of the four groups in mhGAP 2.0 (3): antipsychotics for psychotic disorders, drugs for mood disorders (depressive or bipolar), anticonvulsants and antiepileptics; medications used for management of substance withdrawal, intoxication or dependence.
<p>Community level support</p>	<ul style="list-style-type: none"> • Access to mapping of available community- based mental health psychosocial support • Access to at least one peer support group • Access to at least one parent–infant group

3B. CHILDREN WITH OR AT RISK FOR CZVS

Workforce competencies

- All health care professionals are trained:
 - to recognize CZVS;
 - in supportive communication, basic psychosocial interventions and psychological first aid for children;
 - to recognize, respond to and record child abuse and neglect;
 - in principles of child development, developmental monitoring and support;
 - to recognize the difference between impairment and disability and to understand disability from a rights perspective in line with the Convention on the Rights of Persons with Disabilities; and
 - to advocate for the needs of children and families who are affected or at risk.
- At least one health care professional in every facility has cooperative relations with peer support group(s) and community-based resources and services.
- At least one health care professional per facility is trained to provide:
 - child health care and
 - services for people with mental disorders.
- Complete multidisciplinary care also includes access to health care professionals with knowledge and skills in:
 - neurological conditions in children;
 - child development and early intervention;
 - physiological testing and management of hearing impairments;
 - ophthalmological assessment and management of vision impairment;
 - neuroimaging (e.g. CT, MRI, cranial ultrasound);
 - feeding and nutritional assessment and support; and
 - assessment of physical needs and management by physical therapy, seating and positioning, mobility and assistive devices, and orthotics.
- Additional supportive services may include:
 - orthopedics
 - neurosurgery
 - follow-up support (rehabilitation) and education for children with hearing or vision impairments.
- All community workers should be competent in:
 - developmental monitoring.
 - health and growth monitoring (including head circumference);
 - monitoring of hearing and vision and knowing when to refer for further assessment and intervention (e.g. hearing aids and glasses);
 - monitoring and care for common health needs of children with CZVS (e.g. seizures, irritability, tone management and orthopaedic complications);
 - identifying distress and the mental health needs of affected people and their families;
 - sensitive, supportive communication, provision of initial psychological and medical treatment if needed;
 - appropriate referral and facilitated access to additional services for children identified as at risk or as having developmental difficulties;
 - understanding how to promote child development in routine service provision;
 - awareness of referral pathways in health, education, social and child protection, mental health;
 - mobilizing community and family support, communicating messages that reduce stigma and promote meaningful inclusion;
 - depending on the setting, access to community workers who can conduct:
 - developmental assessments and deliver additional developmental support for children (early intervention) with identified developmental difficulties as a result of CZVS; and
 - physiological hearing testing if appropriate.

3B. CHILDREN WITH OR AT RISK FOR CZVS (CONT.)

<p>Equipment and resources placed in facilities</p>	<ul style="list-style-type: none"> • Every facility has: <ul style="list-style-type: none"> • at least one safe, private location for confidential psychosocial support sessions; • a pharmacy with at least one type of each psychotropic medication category; and • a pharmacy with access to antiepileptic medication for children. • Every facility has access to: <ul style="list-style-type: none"> • laboratories with capacity to test for ZIKV (equipment and testing); • mobility and assistive devices, orthotics; • hearing aids, glasses and ability to review and replace them as children grow and require change; and • systems and equipment for additional feeding support (e.g. orogastric or nasogastric). • Access to additional diagnostic equipment, including: <ul style="list-style-type: none"> • ultrasound, • CT, • MRI, • physiological hearing testing and • ophthalmological testing.
<p>Community level support</p>	<ul style="list-style-type: none"> • Access to mapping of available community- based mental health psychosocial support • Access to at least one peer support group • Access to at least one of the following services: <ul style="list-style-type: none"> • early childhood intervention; • community-based rehabilitation; • community outreach programmes with rehabilitation; • early childhood development programmes in mainstream services. • A transport system that facilitates access to health and social care services for families of children with CZVS, or access to cash transfers to subsidize travel costs to appointments. • Access to inclusive environments, including health care education, social care services, child protection services and child care.

3C. PEOPLE WITH GBS AND OTHER NEUROLOGICAL COMPLICATIONS

<p>Workforce competencies</p>	<ul style="list-style-type: none"> • All health care professionals are trained: <ul style="list-style-type: none"> • In supportive communication with people with GBS and other neurological disorder and their caregivers and families; and • to provide basic psychosocial support to people with GBS and other neurological disorders and their caregivers and families. • To advocate for the needs of affected individuals and their caregivers and families. • At least one health care professional in every facility is trained to: <ul style="list-style-type: none"> • identify GBS and other acute neurological conditions associated with ZIKV by basic neurological examination; • perform an ophthalmological evaluation by direct or indirect ophthalmoscopy; • perform and interpret the results of a lumbar puncture; • intubate and provide critical care to people with GBS and other neurological disorders; • perform and interpret pulmonary function tests; and • perform and interpret neurophysiology tests. • At least one health care professional in every facility has cooperative relations with peer support group(s) and community-based resources and services. • Complete multidisciplinary care includes access to health care professionals with knowledge and skills in cardiac care, pain assessment and management, occupational and physical therapy, wound care, assistive devices and orthotics.
<p>Equipment and resources placed in facilities</p>	<ul style="list-style-type: none"> • Every facility should have: <ul style="list-style-type: none"> • a pharmacy with: <ul style="list-style-type: none"> • at least one type of neuropathic pain medication; • at least one type of every psychotropic medication category in mhGAP 2.0 (3) (see above); • an adequate supply of at least one type of immunotherapy treatment for GBS (intravenous immunoglobulin, therapeutic plasma exchange); • at least one medication for deep-vein thrombosis prophylaxis; • cards to facilitate communication with people with GBS who are on ventilators; and • at least one safe, private location for confidential psychosocial support sessions. • Every facility has access to laboratories with capacity to test for ZIKV (equipment and testing). • Every facility has access to additional diagnostic equipment, including: <ul style="list-style-type: none"> • lumbar puncture kits • sterile procedure items (gloves, masks, etc.) • neurophysiology equipment • peripheral access kits and intravenous fluids • pulmonary function testing equipment • endotracheal tube equipment • telemetry monitors • electrocardiograph machines • blood pressures cuffs • mobility and assistive devices, orthotics.

3C. PEOPLE WITH GBS AND OTHER NEUROLOGICAL COMPLICATIONS (CONT.)

Community level support

- Access to mapping of available community resources
- Access to at least one peer support group
- Access to at least one of the following services:
 - community-based rehabilitation
 - community outreach programmes with rehabilitation services
- A transport system that facilitates access to health and social care services for people with GBS and other neurological disorders, and their caregivers and families, or access to cash transfers to subsidize travel costs to appointments

STORCH, syphilis, toxoplasmosis, other (e.g. varicella-zoster, parvovirus B19), rubella, cytomegalovirus and herpes simplex virus

ii Gender balance and inclusion of representatives of key cultural and ethnic groups among human resources should be promoted to meet the needs of all individuals seeking care and support.

BOX 3. REFERRAL SYSTEMS

An effective referral system ensures successful delivery of care and support. Referral consists of directing a person to another service provider, because they require help that is beyond the expertise or scope of work of the current provider. For example, a health care professional or community worker may refer to a person with complications associated with ZIKV for specialized testing, psychosocial counselling, assistive devices, education or financial assistance or to a social care service agency.

Developing a coordinated referral system

In a successful referral system, participating health facilities or agencies:

- endorse uniform referral documentation (i.e. a referral form);
- agree on specific pathways, procedures and standards for making referrals (e.g. which health facilities or providers are best suited to serve whom); and
- train relevant staff on documentation, standards and procedures and to participate in activities that promote collaboration between and within sectors and disciplines.

These steps should be coordinated through a mechanism such as a stakeholder group. (See section 2.1.)  **2.1**

It is recommended that an inter- and intrasectoral collaborative approach be used, with stakeholders from sectors such as health, social welfare, education and labour as well as civil society organizations that provide services such as peer support.


Annex 2 shows a sample referral form.



Community empowerment

Community empowerment enables communities to increase control over their lives. When public health planners and managers are promoting the empowerment of communities in which there are people with complications associated with ZIKV, they may consider:

- supporting people affected by complications associated with ZIKV in being heard in their communities and by decision-makers to influence the way in which support and care are funded, planned and provided;*
- enabling communities to create an inclusive environment, including strengthening their ownership of the response, removing social exclusion, stigma and discrimination of people affected by complications associated with ZIKV, including children and adults with neurological disorders, their caregivers and families;*
- promoting the role of community workers in the health and social care systems in achieving empowerment; and*
- measuring progress in empowering people affected by complications associated with ZIKV.*

For specific examples of how health care professionals and community workers can promote community empowerment, refer to the Manual for health care professionals, Module 3 and the Manual for community workers, Modules 2 and 3. 

CZVS, GBS and other neurological disorders associated with ZIKV may lead to short- or long-term disabilities. Negative attitudes and behaviour towards people with disabilities, such as the belief that giving birth to a child with a disability is a punishment for a perceived past sin, can result in discriminatory treatment; for example, children bullying other children with disabilities, strangers mocking people with disabilities or denial of their rights. Negative attitudes and behaviour can have an adverse effect on children and adults affected by complications and can have consequences such as low self-esteem, guilt, poor integration within their communities, reduced decision-making and little confidence in claiming their rights.

Stigma can affect not only people affected by complications associated with ZIKV but also their caregivers and families. Individuals may feel a sense of discrimination, exclusion or stress. Stigmatization can lead to isolation of individuals and families, impeding their access to educational, social and health care services.

Community empowerment strategies should comply with the United Nations Convention on the Rights of Persons

with Disabilities (**Box 4**) and the United Nations Convention on the Rights of the Child (**Box 5**). These two conventions challenge the “charity approach”, in which people with disabilities are seen as objects of welfare; instead, they require that people with disabilities, including people affected by complications associated with ZIKV, be considered equal members of society with the same rights as anyone else. Rather than focusing on a person’s impairments, the conventions force a shift in thinking towards the removal of barriers that prevent people from being fully included in society.

Both conventions emphasize that countries should:


- remove barriers, such as stigma and discrimination, that impede the full, equal inclusion of children and adults with disabilities in communities and families;
- develop community-based resources, such as inclusive schools and health and rehabilitation services that are available and accessible to all families, regardless of income; and
- recognize that children are best cared for in family-centred environments that allow the development of attachments, which are critical for children to develop optimally.

BOX 4. THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The United Nations Convention on the Rights of Persons with Disabilities, the first human rights treaty of the third millennium, states in its first article that the purpose of the Convention is to promote and protect the rights and dignity of persons with disabilities (Article 1). The Convention is unique among other international human rights instruments in that its objective clearly focuses on the “dignity” of a marginalized population group. The dignity of people with disabilities, including those with psychosocial disabilities, is highlighted in several articles. Article 3 states that dignity is a key principle that underpins the entire Convention. Article 19 supports the right of people with disabilities to live in the community, with choices equal to those of others, and to their full inclusion and participation in the community. To ensure the development of generations of people with disabilities with a full sense of self-worth and dignity, Article 24 stipulates that the education of children with disabilities must ensure the full development of their human potential, sense of dignity and self-worth. The health care of people with disabilities including those with mental disabilities is addressed in Article 25, which requires “health professionals to provide care of the same quality to persons with disabilities as to others, ... raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards.”

Supporting people affected by complications associated with ZIKV to be heard

Advocacy involves working with people affected by complications associated with ZIKV and with self-advocacy groups for the promotion of the needs and rights of and with people affected. It involves explaining to people their rights and responsibilities, speaking up for those rights and being empowered to make decisions about their own lives.

Community mobilization brings together various stakeholders (see section 1.5)  to enhance care and support to reflect the voices of children with CZVS, their caregivers and families, people with GBS and other neurological disorders and their caregivers and families. It includes raising awareness about the resources and services available to respond to the needs and rights of people affected by complications associated with ZIKV, assisting in their delivery and strengthening community participation to ensure livelihoods, social support and self-help. These promote sustainability and self-reliance beyond the health system response.

A study by the International Federation of the Red Cross and the United Nations Development Programme (5) shows significant gaps in national responses to ZIKV infection in terms of mobilizing community capacity and local assets in endemic and epidemic-prone areas. The role of communities goes beyond controlling the mosquito vector and is an integral part of awareness campaigns, outreach, monitoring and care. Community mobilization is required to increase health system capacity sustainably (particularly in relation to human resources) and to ensure adequate prevention and care management.


Advocacy and community mobilization can be done by individuals but can gain strength when done by a group, engaging the wider community.

Advocacy groups, sometimes referred to as disabled persons' organizations or self-help groups, are groups of people with disabilities who come together to identify priorities and make their needs known. In the context of ZIKV, this involves people affected by complications associated with ZIKV, often with other stakeholders, meeting regularly to identify priorities, actions and messages that they want to communicate and then sharing those messages or actions with the targets of their advocacy. Meetings can take place in person or online, through social media. People with disabilities associated with ZIKV could either be integrated into disabled persons' organizations or self-help groups that are already established or form new independent groups.

"The World Report on Disability suggests steps for all stakeholders – including governments, civil society organizations and disabled people's organizations – to create enabling environments, develop rehabilitation and support services, ensure adequate social protection, create inclusive policies and programmes, and enforce new and existing standards and legislation, to the benefit of people with disabilities and the wider community. People with disabilities should be central to these endeavours."

– Margaret Chan

Public health planners and managers can ensure that the voices of people affected by ZIKV are heard, by:

- facilitating the establishment of advocacy groups that represent people affected by ZIKV and its complications (see Manual for community workers, Module 2)  2 ;
- raising community understanding and interest in supporting the needs of people affected by complications associated with ZIKV;
- inviting representatives of advocacy groups to meetings to contribute to discussions and decisions about support and care for people affected by complications associated with ZIKV;
- building trust and credibility in the community, for instance with local leaders and key stakeholders in the response;
- facilitating the participation of advocacy groups in other forums, e.g. meeting political leaders or senior health personnel and regularly sharing important information about ZIKV;
- providing resources that enable advocacy groups to meet, e.g. meeting venues, as identified by advocacy groups; and
- supporting capacity building for groups, e.g. essential knowledge on ZIKV disease, its complications, advocacy and communication skills or organizational strengthening.

BOX 5. THE UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

The Convention on the Rights of the Child is based on four principles:

- non-discrimination and devotion to the best interests of the child;
- the right to life;
- the right to survival and development; and
- respect for the views of the child.

The Convention lists the fundamental rights of all children, including those with disabilities, namely: the rights to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; to grow up in a family environment; and to participate fully in family, cultural and social life, also recognizing the importance of family assistance and support. Two articles of the Convention refer specifically to children with disabilities: Article 2 outlines the principle of nondiscrimination and includes disability as grounds for protection from discrimination, and Article 23 describes the special efforts countries must make to realize these rights.

Enabling communities to create inclusive environments

Empowering communities involves strengthening their capacity to organize themselves and generate changes in their environment. Many barriers may prevent the full participation of people affected by complications associated with ZIKV in their communities, including negative attitudes, lack of services and poor accessibility. With the right support, communities can identify and make use of their internal resources and knowledge to create environments that are inclusive of all people, including those affected by complications associated with ZIKV.

As the term “community” covers all members of society, when creating inclusive environments, communities should include people with complications associated with ZIKV because they are equal, contributing members of that community.

Public health planners and managers can support communities to create inclusive environments by:

- sharing up-to-date information on ZIKV and associated complications by disseminating evidence-based risk communication messages that do not create fear or feed stigma, e.g. integrated into general public health messages;
- integrating disability-inclusive elements into training packages on complications associated with ZIKV when building capacity for health care professionals and community health workers;
- ensuring that care and support for people with complications associated with ZIKV is available and accessible in the community, with rehabilitation services provided in a community-based approach and other care and support mainstreamed into existing structures rather than creating stand-alone services; and
- adapting social and education services so that they are accessible for all.



Community workers

Community workers have an important role to play in promoting community empowerment. Consideration should be given to building their capacity to offer support for people affected by complications associated with ZIKV and their caregivers and families. Community workers can promote community empowerment by:

- providing mental health and psychosocial support in home-based and community-level initiatives to affected people, including pregnant women in ZIKV-affected areas, families of children with or at risk for CZVS and individuals with GBS or other neurological disorders, including caregivers and families;
- monitoring and following up the health and developmental complications that may be experienced by children with or at risk for CZVS, including building community worker capacity for:
 - supportive communication;
 - addressing the health care needs of children with CZVS (e.g. feeding, irritability management, tone, seizures);
 - monitoring child development (including hearing and vision);
 - promoting every child’s development; and
 - additional strategies for children with CZVS in play, language and communication, movement, everyday activities including positioning, carrying and getting around the community and getting ready for school;
- recognizing when referral is necessary;
- facilitating home- and/or community-based rehabilitation for people with GBS and other neurological disorders; and
- cooperating with existing peer support and self-advocacy groups or facilitating the creation of such groups where they do not exist.

Measuring progress

- Meaningful involvement of people with complications associated with ZIKV in planning and decision-making on enhancing care and support. They can and should make informed choices and decisions.
- Families, communities and social structures promote the well-being and development of their members in inclusive environments. People and their family members come together, form their own groups and organizations or work with existing groups, and work towards solving their common problems.
- Community workers facilitate empowerment and reduce barriers in the community so that people can access information, resources and services related to the ZIKV response locally.

For specific examples of how health care professionals and community workers can promote community empowerment, refer to the Manual for community workers.  

LINKS TO RELEVANT RESOURCES

World report on disability: http://www.who.int/disabilities/world_report/2011/en/

Convention on the Rights of Children: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

Convention on the Rights of Persons with Disabilities:
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

Promoting rights and community living for children with psychosocial disabilities:
http://apps.who.int/iris/bitstream/10665/184033/1/9789241565004_eng.pdf

WHO community-based rehabilitation guidelines: empowerment:
http://apps.who.int/iris/bitstream/10665/44405/5/9789241548052_empower_eng.pdf


Risk communication and community engagement for Zika virus prevention and control:
https://www.unicef.org/cbsc/files/Zika_Virus_Prevention_and_Control_UNICEF_English.pdf

Interagency Standing Committee common monitoring and evaluation framework for MHPSS programmes in emergency settings: <https://interagencystandingcommittee.org/mental-health-and-psychosocial-support-emergency-settings/documents-public/iasc-common-monitoring>



Collaboration

The complications associated with ZIKV and the corresponding health and social implications cannot be addressed by one discipline or one sector alone. In the health care setting, the needs of individuals affected by complications associated with ZIKV can be addressed by multidisciplinary care, promotion of collaboration and communication between and within disciplines and strengthening of referral systems. The planning and implementation of health and social programmes may require the engagement of stakeholders from a wide range of sectors and within sectors, including collaboration between and within government ministries.

For specific examples of how health care professionals and community workers can contribute to multidisciplinary care of people affected by complications associated with ZIKV, refer to the manuals for health care professionals and community workers. 

Multidisciplinary care

Multidisciplinary care is an integrated approach to providing health care (6). Treatment options and planning should be evaluated collaboratively by specialized health care professionals (including allied health care professionals), general health care professionals, care providers (e.g. social workers) and community workers, with the person affected by compli-

cations associated with ZIKV and their caregivers and families. Regular communication among all those involved is critical to multidisciplinary care, including a functioning referral system to ensure access to care and support. Individual, person-centred treatment plans are developed, and delivery of care becomes a shared responsibility. The principles of multidisciplinary care are illustrated in Fig. 2.

FIG 2. FIVE PRINCIPLES OF MULTIDISCIPLINARY CARE AND SUPPORT OF PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKV (7)



Stakeholder engagement

At programme level, collaboration takes place through stakeholder engagement. Assessing, planning and implementing programmes to address the needs of people affected by complications associated with ZIKV requires engagement with stakeholders in a range of sectors (3) (Table 4).

Opportunities to collaborate on all steps can be identified by engaging with stakeholders. Collaboration among stakeholders not only maximizes access to appropriate care and support but also promotes sharing of resources and knowledge while avoiding duplication and waste. For example, surveillance and laboratory staff can share information with clinicians on the association between ZIKV and neurological disorders and congenital malformations.

Practical tips

Key characteristics of collaboration:

- inclusive, non-hierarchical participation;
- participant responsibility for ensuring success;
- a common sense of purpose and definition of problem;
- education of participants by each other;
- identification and testing of multiple options;
- sharing solutions; and
- keeping people informed as situations evolve.

Collaborate with other sectors when:

- planning and carrying out a situation analysis;
- identifying priorities;
- adapting materials;
- building capacity;
- planning and doing surveillance, monitoring and evaluation (Box 6);
- enhancing care;
- planning and performing advocacy activities; and
- promoting knowledge-sharing.

Collaboration may be horizontal (for example within government) or vertical (for example between government and community organizations).

Measuring progress

- Multidisciplinary care and referral systems established.
- Inclusion of sectors involved in enhancing care for people affected by complications associated with ZIKV.
- Inter-sectoral plans developed.

LINKS TO RELEVANT RESOURCES

Advancing the health in all policies approach in the Americas: What is the health sector's role?

A brief guide to recommendations for promoting inter-sectoral collaboration:

http://www.paho.org/hq/index.php?option=com_docman&task=doc_view&Itemid=270&gid=30677&lang=en

Stakeholder involvement: <http://www.who.int/dietphysicalactivity/griffiths-stakeholder-involvement.pdf>

Policy brief 5: Inter-sectoral collaboration for mental health in South Africa:

http://www.who.int/mental_health/policy/development/MHPB5.pdf

TABLE 4. STAKEHOLDERS TO BE CONSIDERED FOR PROMOTING COLLABORATION

Sector	Examples
General and specialist health services and care providers	Primary care workers, nurses, neurologists, psychiatrists, physical therapists, occupational therapists, speech therapists, paediatricians, psychologists, ophthalmologists, audiologists, community workers, social workers, inpatient or outpatient service providers, outreach care workers
People affected by complications associated with ZIKV	Groups or individuals living with GBS, children living with CZVS, caregivers and families
Community support	Self-help groups, faith-based groups, savings groups, recreational groups, mothers' groups, women's groups, youth groups, cultural groups, helplines
Education and livelihood	Schools, education, income-generating or vocational training programmes
Nongovernmental organizations	Local and international civil society organizations (e.g. those working in health, education, disability rights, legal aid, child protection services, gender-based violence or psychosocial support)
Government services and benefits	Health, education and justice systems, child welfare, pensions, disability, social welfare, transport

MODULE 2

Strengthening the long-term response to Zika virus

This module provides strategies for strengthening the long-term response to ZIKV under the following headings:

- 2.1 *Establishing a stakeholder group*
- 2.2 *Situation analysis*
- 2.3 *Workforce capacity building*
- 2.4 *Surveillance*
- 2.5 *Research*

BOX 6. MONITORING AND EVALUATION

Monitoring and evaluation are essential parts of programmes for managing complications associated with ZIKV. They indicate whether a programme is effective. They can identify programme areas that are reaching their target and aspects of a programme that should be adjusted or replaced. Information from monitoring and evaluation can lead to better decisions about investments or can demonstrate to programme implementers and funders that their investments are paying off. The phrase “What gets measured gets done” summarizes the importance of monitoring and evaluation in programme planning and implementation. The types of data usually required are on: inputs for implementing the programme’s activities, the activities themselves and their outputs (i.e. immediate effects). The outputs of some programmes are intended to lead to outcomes (i.e. intermediate effects) that in turn are intended to have impacts on people.

Monitoring is routine tracking of how well programme activities are being implemented from data collected regularly and continuously. Monitoring is used to assess whether planned activities are done according to schedule and are progressing towards identified targets. It is also used to monitor use of services.

Evaluation is the systematic, objective assessment of a programme, whether current or completed. It is done periodically to measure the quality of implementation and/or the extent to which the intended target population uses services (coverage) and/or the extent to which the impact is achieved (e.g. symptom reduction, improved quality of life, reduced morbidity or mortality).

Domains for measurement

Indicators are measures (activity-related, population-based coverage and health status) that are repeated to track progress towards objectives. In this Toolkit, inputs, activities and outputs are assessed from **activity-related indicators**, outcomes are usually assessed from population-based coverage indicators, and impact is assessed from **health status indicators**.



Establishing a stakeholder group

Public health planners and managers should establish and collaborate with a stakeholder group that includes members from various relevant government ministries and departments (Table 5) and other national and international stakeholders (Table 6). Stakeholder groups are instrumental in promoting the mainstreaming of health and social care services while strengthening existing services so that the needs of people affected by complications associated with ZIKV are addressed comprehensively. An important role of the stakeholder group is to advocate to policy-makers and funding agencies for the enhancement and scaling up of services in an approach that offers respect and dignity.

Health care professionals and community workers can contribute to stakeholder groups because of their understanding of the needs of people affected by complications associated with ZIKV.







For examples of skills and knowledge that health care professionals and community workers may have, refer to the manuals for health care professionals and community workers.  

TABLE 5. GOVERNMENT INSTITUTIONS AND THEIR POTENTIAL ROLES IN A STAKEHOLDER GROUP

Sector	Role
Health (including focal points who can plan neurological, mental health and psychosocial support, vision and hearing care, nutrition, laboratory services, child and maternal health, primary care, reproductive health, human resources, risk communication and sanitation)	<ul style="list-style-type: none"> • Ensure neurological assessment and management of adults with GBS and other neurological disorders and children born with or at risk for CZVS. • Ensure early intervention for children born with or at risk for CZVS. • Assess mental health and psychosocial needs and facilitate capacity building in psychosocial support. • Monitor and respond to the targeted population's needs with regard to vision, hearing and nutrition. • Enhance and monitor laboratory capacity for surveillance of ZIKV and associated complications and for diagnostic testing. • Identify gaps in health and social care systems, and support capacity building in health and social care. • Provide education about prevention of ZIKV infection and counselling on contraceptive and discontinuation of pregnancy. • Conduct surveillance and control of Aedes mosquitoes, including management of health centre wastewater. • Optimize referral system between relevant disciplines and sectors.
Allied health (including focal points for rehabilitation services such as occupational and physical therapy and speech therapy)	<ul style="list-style-type: none"> • Integrate rehabilitation for children born with CZVS and adults with GBS and other neurological disorders into existing rehabilitation services, including in the community. • Optimize referral system between relevant disciplines and sectors.
Social welfare (including focal points to address disability issues)	<ul style="list-style-type: none"> • Ensure social protection services to mitigate potential socio-economic impacts on affected families, and ensure access for women and children. • Provide psychosocial support for people affected by complications associated with ZIKV, including caregivers and families. • Promote access to services for adults and children with disabilities associated with ZIKV. • Promote the rights of people with disabilities in compliance with the United Nations Convention on the Rights of Persons with Disabilities. • Optimize referral system between relevant disciplines and sectors.
Education	<ul style="list-style-type: none"> • Prepare educational facilities and systems to adapt to the needs of children with and at risk for CZVS, and offer educational services according to the context. • Optimize referral system between relevant disciplines and sectors.
Livelihood	<ul style="list-style-type: none"> • Create work opportunities for people affected by complications associated with ZIKV, including caregivers and families. • Ensure that women have equal opportunities in accessing work opportunities. • Create policies and strategies to promote inclusive employment (e.g. supported employment, sick and disability leave from work). • Optimize referral system between relevant disciplines and sectors.

Steps

1. *Identify government and nongovernment institutions that can address the complications associated with ZIKV (Table 5).*
2. *Invite other stakeholders to join the group to ensure that the needs of people affected by complications associated with ZIKV are adequately represented. (Table 6).*
3. *Set the purpose and terms of reference of the group.*
4. *Define areas of action for the team and see related sections, such as*
 - situation analysis  2.2
 - workforce capacity building  2.3
 - surveillance  2.4
 - research  2.5
5. *Identify the main roles and responsibilities of each group member.*

Practical tips

- Before establishing the stakeholder group, determine how the group will be managed; for example:
 - the ministry and department that will provide the resources for the group and
 - the person who will coordinate the group.
- One or more stakeholder groups might be necessary, depending on the geographical area or region to be covered. Groups can meet in person or communicate online, depending on the size and resources of the country.
- Build on an existing body or group, such as a health committee or community advisory group, rather than establishing a new one. Groups could be merged or a new group could be established with the participation of members from several groups.
- Form smaller action groups or task forces for specific activities, e.g. one group to conduct a situation analysis and another to build capacity. Clearly identify the functions of each task force and the role of each of its members.

Measuring progress

- Stakeholder group established, with terms of reference.
- Number of stakeholder group meetings held
- Clear responsibility for coordinating and resourcing meetings defined.
- Meeting action points followed through.

TABLE 6. OTHER STAKEHOLDERS THAT MIGHT PARTICIPATE IN A STAKEHOLDER GROUP OR ACT AS ADVISERS

Other stakeholders	Potential role
People affected by complications associated with ZIKV, including caregivers and families	<ul style="list-style-type: none"> Individuals with GBS and other neurological disorders, caregivers and families could ensure that the services and care provided reflect the needs and interests of services users. Advocate on behalf of children and adults affected by complications associated with ZIKV who cannot advocate for themselves. Ensure that the development of services meets the needs and interests of people affected by complications associated with ZIKV and their caregivers and families.
Civil society groups (e.g. disability advocacy groups)	<ul style="list-style-type: none"> Provide human and physical resources when required, and communicate the interests of community members.
Government and nongovernment funding agencies (potential or actual)	<ul style="list-style-type: none"> Understand gaps in financial resources. Show how the health and social care system might access financial support for activities to address the needs of people affected by complications associated with ZIKV.
Nongovernmental organizations	<ul style="list-style-type: none"> Identify activities that can be managed by nongovernmental organizations, including providing resources (human, physical or financial) for people affected by complications associated with ZIKV and advocacy to promote the rights of people affected.
Academic institutions	<ul style="list-style-type: none"> Identify areas for research on complications associated with ZIKV. Foster partnerships with other stakeholders for research activities.
Local leaders (e.g. religious figures, traditional healers)	<ul style="list-style-type: none"> Represent community members, their concerns and interests with regard to complications associated with ZIKV.
Health and social care providers, including allied health and community providers	<ul style="list-style-type: none"> Communicate the interests and concerns of health and social care providers, from specialists to general health care professionals, with regard to complications associated with ZIKV. Identify gaps in the workforce in order to scale up services. Advocate for feasible workloads during scaling-up of service delivery.

LINK TO RELEVANT RESOURCE

Zika strategic response plan (Updated 30 June 2016):

<http://apps.who.int/iris/bitstream/10665/246091/1/WHO-ZIKV-SRF-16.3-eng.pdf>

BOX 7. LESSONS LEARNT FROM BRAZIL'S NATIONAL NETWORK OF EXPERTS ON ZIKA VIRUS AND ASSOCIATED COMPLICATIONS.

After the declaration that the ZIKV outbreak in Brazil was a public health emergency, a group composed of experts, managers and civil society representatives formed a national network of experts on ZIKV and associated complications. The aim of the group is to "enhance the formulation and implementation of actions and policies related to the ZIKV in Brazil."

The objectives include:

- Provide the Ministry of Health with information on research related to ZIKV and related diseases under surveillance, prevention, control, social mobilization, health care and scientific and technological development.
- Contribute to the formulation and improvement of protocols and other technical documents from the Ministry of Health on the subject.
- Strengthen epidemiological analytical capacity and priority research projects on the subject to the unified health system.
- Seek potential sources of funding for related research, optimizing the selection and formation of partnerships.
- Promote participation in research, development and technological innovation.
- Support and organize events with experts in this area.
- Encourage the development of multicentre studies on ZIKV and related complications.

The objectives are achieved by working groups:

- Health care of women and children
- Monitoring of the national public health laboratory system
- Vector control innovations
- Research, translation and dissemination of knowledge
- Integrated surveillance of congenital changes related to infection during pregnancy
- Bioethics
- International partnerships.





Situation analysis

The main objective of a situation analysis is to form a basis for planning, adaptation and implementation of improved care and support for people affected by complications associated with ZIKV. The analysis should be comprehensive, multidisciplinary and cover all levels of the health and social care systems. Needs and available resources in both facilities and the community should be identified, including:

- strengthening of the primary care system and the capacity of human resources to integrate further skills and tasks;*
- policies, strategies and legislation relevant to people affected by complications associated with ZIKV;*
- the availability of care in facilities and in the community (for example, occupational and physical therapy, neurological care, ear and eye care);*
- the availability and quality of laboratory and diagnostic services for testing for ZIKV and GBS; and*
- the knowledge and skills of general health care professionals and community workers, including the ability to identify and manage CZVS and GBS and to provide psychosocial support to caregivers and families.*

The report should describe the current situation and identify the main barriers to strengthening services and actions to overcome the barriers. A thorough analysis of the context will set the basis for supporting people affected by complications associated with ZIKV.

Steps

1. *The information collected in a thorough situation analysis should answer the questions listed below. (Box 8).*
2. *From the responses to the questions, review the framework for enhancing delivery of care and support (see section 1.2)  1.2 and requirements for mainstreaming care and support into health care settings (see section 1.3)  1.3 to identify gaps in care and support.*
3. *Summarize the main findings, and discuss the results with relevant stakeholders.*
4. *Identify the main barriers to extending services and actions to overcome the barriers.*
5. *Finalize the report and disseminate it, with recommendations for action.*

Practical tips

- Focus the situation analysis on action rather than simply collecting information. Collecting too much information wastes resources and places an unnecessary burden on interviewees.
- Assess both needs and resources to increase the likelihood that the resulting action plan builds on existing support and resources.
- **Annex 3** provides additional information about conducting a situation analysis, including how and from where to collect information and the main elements of the report.
- The findings of the situation analysis can be used to identify and prioritize actions (**Annex 4**).



BOX 8. QUESTIONS TO BE ANSWERED BY A SITUATION ANALYSIS

- ? What are the needs of people affected by complications associated with ZIKV?
- ? What resources are available in the community to meet the needs of people affected by complications associated with ZIKV?
- ? What are the national policies, strategies and legislation pertaining to mental health, disabilities, rehabilitation and neurology?
- ? What health and social care is currently provided for ZIKV-related complications, and what are the gaps?
- ? What diagnostic resources are available?
- ? What financial resources are available?
- ? What is the human resource capacity of the country or region to provide health and social care services for people affected by complications associated with ZIKV? What are the capacity building needs?
- ? What is the geographical distribution of services, including specialist care?
- ? What are the belief systems and the care-seeking behaviour with regard to mental health, disabilities, rehabilitation and neurology in the country or region?
- ? What barriers are there to enhancing health and social care services, such as stigma and discrimination towards people affected by complications associated with ZIKV? What are the ways to potentially overcome the barriers?




2.3

Workforce capacity building

In order to offer better care and support to people affected by complications associated with ZIKV, the health system workforce must have the necessary skills and be adept in providing care.

Table 3 (see section 2.1)   outlines the workforce requirements for mainstreaming care and support. Training health care professionals and community workers is not enough; it must be completed by adequate ongoing supervision, support of community leaders and provision of resources.

Enhancing care and support to meet the needs of people affected by complications associated with ZIKV will be a challenge in some countries because of shortages in human resources in health services. Therefore, the potential of the existing health workforce must be optimized, especially at primary and secondary care levels. Distributing tasks and responsibilities among cadres of health workers is considered a promising strategy for improving access to and the cost-effectiveness of health systems.

For further details of the content that can be covered when building the capacity of health care professionals and community workers to provide care and support for people affected by complications associated with ZIKV, refer to the manuals for health care professionals and community workers.   

Access to care and support may be improved by building the capacity of health care professionals and community workers to perform certain tasks that have previously been provided only by cadres with longer (and sometimes more specialized) training. This strategy, task sharing, might be particularly attractive in countries experiencing outbreaks of ZIKV, because it may improve access to care and support rapidly (9). The guidance provided in this section can be used to build the capacity of health care professionals and community workers and is complementary to a task sharing approach.

The WHO Toolkit for the care and support of people affected by complications associated with Zika virus includes two other manuals:

1. Manual for health care professionals:

- Directed at health care professionals in primary care facilities who will be involved with children with or at risk of CZVS and their caregivers and families, including professionals involved in antenatal care;

and/or

- Directed at health care professionals in primary care facilities who will evaluate and provide care and support to people with GBS or other neurological conditions (which may be associated with ZIKV), as well as their caregivers and families.


2. Manual for community workers

- Directed at community workers from a range of sectors who are responsible for direct care, monitoring and following up children with or at risk of CZVS, people with GBS and other neurological disorders, as well as caregivers and families

An approach that includes training and continuous supervision is commonly used in building capacity in health and social care systems (Fig. 3). A master facilitator trains other facilitators in a “training of facilitators and supervisors” workshop. The trained facilitators then train and provide support and supervision to general health care professionals and community workers. (See facilitator’s guidance notes available upon request from zika-toolkit@who.int).

Before conducting capacity building, training and supervision materials should be systematically adapted to the context (Annex 5) in order to:

- ensure that the capacity building materials can be used in local systems;
- ensure that the capacity building materials are acceptable in the local socio-cultural context;
- use local terms to facilitate communication;
- clarify referral pathways;
- ensure that the capacity building materials are consistent with relevant national treatment guidelines and policies; and
- ensure that the monitoring and evaluation indicators are consistent with the national health information systems (Box 6).

Adaptation is also a good way of engaging with community leaders and giving them an opportunity to participate, learn the materials thoroughly and support subsequent implementation. Official endorsement, or even an official launch, of the adapted materials may be useful. The people involved in the adaptation and the master facilitators may belong to stakeholder group. (See section 2.1.)  **2.1**

Various training methods should be considered and chosen according to the context. These include:

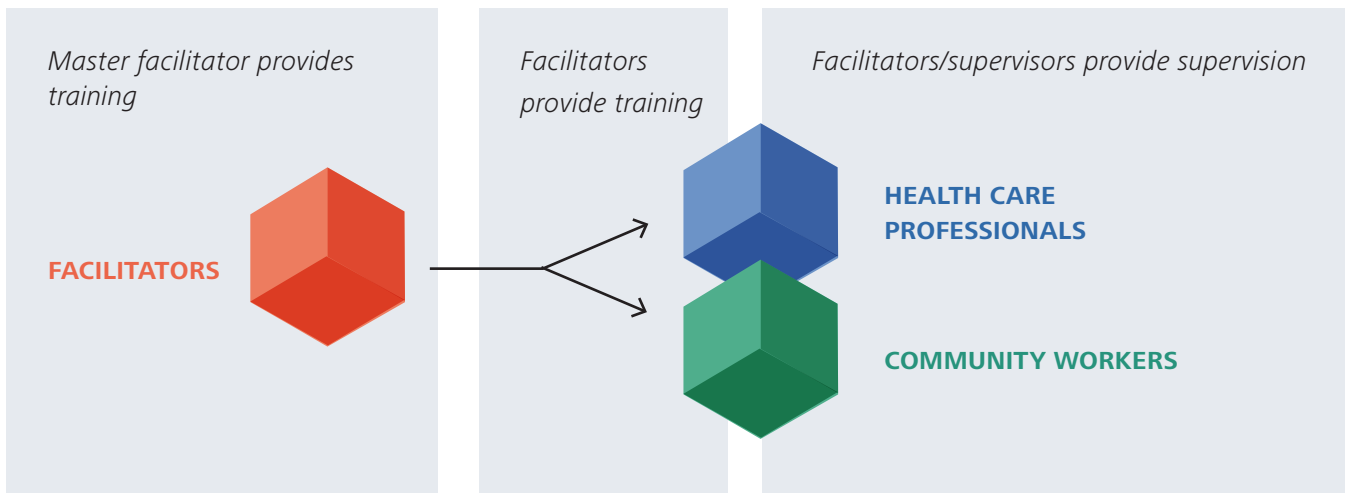
- PowerPoint slides,
- role play,
- demonstration videos and
- self-care activities.

Steps

1. Identify the facilitators and participants in capacity building activities (**Annex 6**).
2. Adapt the training materials to the context (**Annex 5**).
3. Plan training and supervision, taking into account materials and logistics (**Annex 7**).

Practical tips

- Professional associations may be sources for recruiting master facilitators and facilitators.
- Ideally, they should be:
 - specialists in a health care discipline relevant to ZIKV and its complications (e.g. paediatricians, psychiatrists, psychiatric nurses, neurologists, allied health care and professionals);
 - physicians or nurses with training, clinical experience or administrative experience in managing complications associated with ZIKV;
 - people who are already supervisors in the general health system.
- Master facilitators and facilitators should have good communication and problem-solving skills and, ideally, experience in training and facilitation. They should be available to provide support and supervision, including regular supervisory visits. If facilitators are unable to also act as supervisors, separate supervisors may have to be recruited and trained.
- Depending on the context, people affected by complications associated with ZIKV could be invited to training courses to give testimonies. The course planner should prepare for such guests, by providing, for example, transport, access to the training room and building and meals. It may also be best for the guest to be accompanied by someone who knows him or her well (e.g. family, service provider). The dignity of all such guests must be maintained.
- For optimal learning of skills and knowledge, training methods should comprise a combination of interactive and mixed sessions (**Box 9**).

FIG. 3. APPROACH TO CAPACITY BUILDING

BOX 9. EFFECT OF MEDICAL EDUCATION ON BEHAVIOUR OF HEALTH PROFESSIONALS AND HEALTH CARE OUTCOMES

A landmark systematic review of randomized controlled trials of formal didactic and interactive education methods covered 14 studies and 17 interventions (10). Nine resulted in positive changes in professional practice, and three of four interventions altered one or more measures of health care outcomes.

Seven studies that provided information suitable for reanalysis found no significant effect of standard educational methods on practice, while interactive and mixed educational sessions were associated with a significant effect. Techniques such as case discussions, role-play and actual practice sessions were effective in changing the performance of health care professionals. Sequenced sessions of learn–work–learn, in which learning is translated into practice and reinforced at a further session, were effective.

These findings were reinforced more recently by a Cochrane review of 81 randomized controlled trials of different educational strategies in which an objective measure of professional practice or health care outcomes was reported (11). The results suggested that educational sessions alone only marginally improve professional practice and achievement of treatment goals for patients. The effect on professional practice tended to be small, and the effect on patient outcomes was generally smaller. It appeared that mixed interactive and didactic education was more effective than either alone (12).



2.4

Surveillance

In the context of ZIKV, surveillance is the continuous, systematic collection, analysis and interpretation of data on complications associated with ZIKV. Countries affected by ZIKV can use surveillance to set priorities and inform public health policy and strategies to enhance care and support for people affected by complications associated with ZIKV. Table 7 lists the objectives of surveillance in this context, with examples.

TABLE 7. OBJECTIVES OF A SURVEILLANCE SYSTEM FOR COMPLICATIONS ASSOCIATED WITH ZIKV

Objective	Example
<i>Provide early warning of a potential public health emergency</i>	<ul style="list-style-type: none"> • Detection of a sudden increase in the incidence of CZVS in newborns • Unusual increase in the number of people with GBS may indicate a ZIKV outbreak
<i>Monitor epidemiological trends during a public health emergency</i>	<ul style="list-style-type: none"> • Increase or decrease in the incidence of infants born with CZVS • Change in the distribution of cases of GBS, which may indicate a change in local ZIKV transmission
<i>Assess the impact of an intervention</i>	<ul style="list-style-type: none"> • Diagnosis of ZIKV infection during pregnancy, with continued monitoring for adverse health events during pregnancy and after the birth
<i>Plan services to meet the health care needs of people affected by complications associated with ZIKV in a public health emergency</i>	<ul style="list-style-type: none"> • Services to meet the needs associated with the spectrum of disorders seen in CZVS • Rehabilitation services for short- and long-term disability associated with GBS and other neurological disorders

Overall considerations in surveillance of complications associated with ZIKV

- Encourage strong leadership and commitment for surveillance from the government and funding agencies.
- Respect local public health legislation and the International Health Regulations (2005). Reporting to WHO allows compilation of broader surveillance data and their dissemination (**Annex 8**).
- Establish a working group for surveillance of complications associated with ZIKV, made up of diverse stakeholders including epidemiologists, laboratory personnel, data managers and experts in maternal and child health and neurology. Clinical and academic members should be involved in designing and conducting surveillance.
- Review the health information system to identify possibilities for integrating surveillance of complications associated with ZIKV into programmes such as pregnancy and birth registers and active poliomyelitis surveillance.
- Ensure that surveillance is adapted to local resources and capacity, including laboratory networks and expected short- and long-term financial resources. Standard case report forms that meet local and international reporting requirements should be adapted. **Annexes 9 and 10** provide examples.
- Ensure that the surveillance systems for complications associated with ZIKV are flexible enough for inclusion of new aspects in the evolving spectrum of congenital birth defects and neurological disorders.
- Use standard case definitions for both ZIKV infection and associated complications.
- Build the capacity of health care professionals to detect ZIKV infection and associated complications, including laboratory testing for ZIKV and appropriate assessment, with the “building back better” strategy (2) (**Box 2**).
- Train health care professionals in reporting complications potentially associated with ZIKV, and coordinate surveillance activities among partners at all levels of the health system.
- Strengthen laboratory capacity to detect ZIKV infection, including protocols for specimen collection and storage, diagnostic algorithms and case definitions. Laboratory results should be integrated into epidemiological surveillance data management systems.
- Strengthen communication and transport systems.
- Establish a data management plan, including data collection, a dedicated data management system, data entry and data sharing. Data quality should be assessed regularly.
- Analyse and disseminate epidemiological data regularly, such as in periodic public health reports.
- Establish activities to monitor the long-term consequences of complications associated with ZIKV.
- Conduct community outreach activities to improve recognition of the signs and symptoms of complications associated with ZIKV.

Surveillance of CZVS

CZVS refers to the spectrum of disorders, including microcephaly, that have been causally associated with ZIKV infection during pregnancy. The spectrum will evolve as new data become available. Activities should include surveillance of ZIKV infection among pregnant women and congenital disorders that could be CZVS.

Objectives

- Estimate the baseline incidence of births and trends of the congenital syndromes associated with ZIKV, including microcephaly.
- Identify ZIKV infection among pregnant women, and monitor them for adverse health events throughout pregnancy and after birth.
- Identify new cases of congenital disorders, including microcephaly.
- Identify ZIKV infection among newborns.

Considerations

- Estimate the baseline incidence of disorders from available data sources, including birth registers, hospital administrative codes databases, insurance company databases and hospital records of births.
- Ensure that CZVS surveillance is reviewed and updated routinely as new data on congenital disorders associated with ZIKV become available.
- Consider integrating surveillance of CZVS into existing birth defects surveillance systems.
- Design either an ad-hoc surveillance subsystem or integrate surveillance into an existing system specifically for the identification of newborns with CZVS, miscarriages and fetal deaths in areas with risk for ZIKV circulation. Surveillance should be supported by other sources of information, such as registers and data from referral hospitals.
- Consider using “event surveillance” and “sentinel surveillance” of birth defects, particularly in resource-limited contexts.

- Strengthen awareness about CZVS at all levels of the health system, particularly among health care professionals (e.g. sonographers, obstetricians and maternal and child practitioners), to ensure identification and reporting of congenital disorders. Professional associations may help in communicating such information to relevant health care professionals.
- Regularly analyse the data from CZVS surveillance as well as from established registries to make locally relevant recommendations for clinical care, services for pregnant women and for families affected by ZIKV and for prevention of ZIKV infection during pregnancy.

Surveillance of GBS and other neurological disorders

ZIKV has been identified as a trigger of neurological conditions, including GBS. Surveillance activities should include confirmation of neurological diagnosis and detection of ZIKV infection. (See **Box 11** for an example of emergency public health surveillance of GBS and other neurological conditions.)

Objectives

- Estimate the baseline incidence of GBS.
- Identify new cases of GBS, and test for ZIKV infection.

Considerations

- Use sources including hospital administrative codes databases, insurance company databases, clinical records and data from tertiary referral hospital to estimate the baseline incidence.
- Consider adapting systems for the surveillance of acute flaccid paralysis (AFP) in poliomyelitis to detect cases of GBS (**Box 10**).
- Investigate reported cases of GBS by confirming the diagnosis, recording the history of previous illness and progression of neurological signs, reviewing medical records and collecting specimens for laboratory testing,

- Confirm the final neurological diagnosis against standardized criteria, such as the Brighton Collaboration criteria for GBS (13).
- Monitor variables that might indicate neurological complications associated with ZIKV, such as increases in the use of intravenous immunoglobulin G, the number of cases of AFP and demand for rehabilitation and physical therapy services.
- Support health care professionals in timely diagnosis and treatment of people with GBS and other neurological disorders to improve their prognosis, including training health care professionals in clinical management and ensuring the availability and accessibility of treatment, such as intravenous immunoglobulin G and long-term rehabilitation services.
- Analyse epidemiological trends, including the incidence and clinical presentation of cases of GBS with evidence of ZIKV infection.

BOX 10. USE OF A POLIOMYELITIS SURVEILLANCE SYSTEM FOR DETECTING ZIKV OUTBREAKS

ZIKV has challenged outbreak surveillance in many at-risk, low-resource countries. WHO is exploring cost-effective methods to detect cases of ZIKV infection and associated neurological complications. One method is adapting the existing infrastructure for polio surveillance (14).

Role of the polio surveillance network

As part of the global polio eradication programme, an extensive, active network for the detection of AFP has been established. Every year, 100 000 cases of AFP worldwide are investigated in surveillance systems, which exist in 90% of Member States.

Use of the polio surveillance network for surveillance of other diseases

The network has been used effectively to detect diseases such as measles, Ebola disease and yellow fever. For example, it was used to identify cases of Ebola disease in Nigeria. The system includes surveillance of measles outbreaks in India.

Use of the polio surveillance network to indicate a ZIKV outbreak

Cases of AFP reported routinely to the Global Polio Eradication Initiative could indicate either polio or GBS, both of which are due to infectious agents. Detection of an increase in the number of cases of GBS in the AFP surveillance system may provide early warning of a ZIKV outbreak.

Use of polio surveillance systems to identify complications associated with ZIKV

In a study in the Pacific islands (15), researchers found a significant increase in the number of reported cases of AFP on the Solomon Islands concurrently with a ZIKV outbreak. To further investigate this potential correlation, they analysed published and unpublished data on ZIKV outbreaks in 21 Pacific Islands between 2007 and 2015 and compared the results with data in the Global Polio Eradication Initiative database on the reported and expected numbers of AFP in children under 15 years of age. They found no conclusive evidence that routinely reported cases of AFP in children were useful for detecting a significant increase in the number of people with GBS in countries and areas with small populations.

Strengthening of polio surveillance systems to monitor cases of GBS potentially associated with ZIKV

AFP surveillance could be strengthened to monitor cases of GBS. For example, extending AFP surveillance to adults could improve surveillance for GBS, which generally affects older people, whereas polio generally affects children under 15 years of age.

BOX 11. EMERGENCY PUBLIC HEALTH SURVEILLANCE OF GBS AND OTHER NEUROLOGICAL CONDITIONS IN PUERTO RICO

Areas recently affected by ZIKV, such as Brazil, Colombia and French Polynesia, have reported concurrent increases in the numbers of reported cases of GBS. In December 2015, the Puerto Rico Department of Health reported the island's first locally acquired case of ZIKV. In January 2016, a person presented to a hospital in San Juan with numbness and progressive weakness, preceded by two days of rash. GBS was subsequently diagnosed, and laboratory analysis provided serological evidence of recent ZIKV infection.

In February 2016, the Puerto Rico Department of Health, with assistance from the US Centers for Disease Control and Prevention, set up an emergency public health surveillance system for GBS and other neurological conditions. The objectives of the system were to monitor epidemiological trends, provide arbovirus testing and support health care professionals (16). The system comprised:

- reporting suspected cases on a GBS case report form¹ to identify new cases and monitor trends;
- laboratory testing of patient specimens by real-time reverse transcription polymerase chain reaction and enzyme-linked immunosorbent assay for immunoglobulin M to determine current or recent infection with Zika, dengue or chikungunya viruses;
- retrospective chart review of all reported suspected cases to confirm the final neurological diagnosis on the Brighton Collaboration criteria (13) and collect additional clinical data;
- continuous analysis of epidemiological and clinical data to inform public health action;
- estimating the baseline GBS incidence and determining when the incidence exceeded that expected and returned to baseline (17);
- engaging health care professionals, such as by publishing a biweekly report and training, to strengthen the surveillance system and raise clinical awareness for timely diagnosis and treatment of people with GBS and other neurological disorders;
- evaluating the surveillance system and reviewing hospital medical records to identify unreported cases; and
- conducting follow-up interviews to assess the long-term disability of people with GBS and other neurological disorders.

Emergency public health surveillance in Puerto Rico resulted in timely monitoring of cases of GBS throughout the local ZIKV outbreak. Continued data analysis is being conducted to better understand the association between ZIKV infection and GBS, with rigorous case definitions.

¹The GBS case report form is available in both Spanish (<http://www.salud.gov.pr/Sobre-tu-Salud/Documents/Espa%F1ol.pdf>) and English (<http://www.salud.gov.pr/Sobre-tu-Salud/Documents/ingl%c3%a9s.pdf>).

Practical tips

- Consider use of active or enhanced surveillance methods to complement usual surveillance.
- Consider the role of civil society organizations (1) in strengthening communities' capacity to participate actively in surveillance, identify communities affected by ZIKV that were potentially missed in regular surveillance and provide input for the adaptation of public health messages to improve surveillance.
- Surveillance may be facilitated by use of platforms such as mobile telecommunications and Internet registries.

LINKS TO RELEVANT RESOURCES

Zika strategic response plan (updated 30 June 2016). Geneva: World Health Organization; 2016:
<http://apps.who.int/iris/bitstream/10665/246091/1/WHO-ZIKV-SRF-16.3-eng.pdf>.

Assessment and management of Guillain-Barré syndrome in the context of Zika virus infection (interim guidance update 17 August 2016). Geneva: World Health Organization; 2016:
http://apps.who.int/iris/bitstream/10665/204474/1/WHO_ZIKV_MOC_16.4_eng.pdf.

Screening, assessment and management of neonates and infants with complications associated with Zika virus exposure in utero (rapid advice guideline, 30 August 2016). Geneva: World Health Organization; 2016:
http://apps.who.int/iris/bitstream/10665/204475/1/WHO_ZIKV_MOC_16.3_eng.pdf.

Guidelines for surveillance of Zika virus disease and its complications. Washington DC: WHO Regional Office for the Americas; 2016:
http://iris.paho.org/xmlui/bitstream/handle/123456789/28405/9789275118948_eng.pdf?sequence=1&isAllowed=y.

Birth defects surveillance: a manual for programme managers. Geneva: World Health Organization, National Center on Birth Defects and Developmental Disabilities (United States Centers for Disease Control and Prevention), International Clearinghouse for Birth Defects Surveillance and Research; 2014:
http://www.who.int/nutrition/publications/birthdefects_manual/en/

International Health Regulations (2005). Geneva: World Health Organization; 2016:
<http://www.who.int/ihr/publications/9789241580496/en/>.



Research

The evidence linking ZIKV infection in pregnant women with CZVS in their fetuses and also with GBS and other neurological disorders is strong and growing. Nevertheless, many questions for research and public health remain to be addressed to better understand the implications of ZIKV infection for children and adults. Evidence is required to strengthen essential public health guidance and actions to prevent and limit the impact of ZIKV infection and its complications on people around the world.

Priorities for research

WHO's ZIKV research agenda (18) lists three priorities for research: characterization; prevention and control; and women, communities and health systems. **Table 8** provides examples of studies on complications associated with ZIKV under each priority.

TABLE 8. PRIORITIES FOR RESEARCH AND EXAMPLES OF STUDIES ON COMPLICATIONS ASSOCIATED WITH ZIKV

Priority	Type of study	Example
Characterization	Epidemiological	<ul style="list-style-type: none"> • Baseline rates of birth defects and GBS in the context of ZIKV outbreaks • Rates and types of complications in areas of endemic transmission and in new outbreaks • Geographical variation in types of complications (e.g. modifying elements)
	Clinical	<ul style="list-style-type: none"> • Risks for adverse outcomes of pregnancy (all congenital abnormalities) in women infected with ZIKV and in uninfected women • Cohort study initiated in early pregnancy of pregnancy outcomes in women with ZIKV infection • Follow-up for at least two years of infants born to infected and uninfected mothers • Complications of ZIKV in men and women (autoimmune disorders such as GBS)
	Laboratory diagnostics	<ul style="list-style-type: none"> • Sensitivity of laboratory tests, including effect of timing on serology and laboratory tests such as Trioplex rRT-PCR designed to detect ZIKV, dengue and chikungunya viruses • Cross-reactivity with other flaviviruses • Role of lab in diagnosis of infants with CZVS recognized later (outside of newborn period)
Prevention and control	Vaccine development	<ul style="list-style-type: none"> • Efficacy, safety and use of vaccines in pregnancy
	Vector control	<ul style="list-style-type: none"> • Eradication of mosquitoes
	Treatment	<ul style="list-style-type: none"> • Antiviral treatment to prevent transmission or diminish effects on developing fetuses • Course of treatment for GBS
	Regulatory support	<ul style="list-style-type: none"> • For vaccines, diagnostics, therapeutics and preparation and characterization of reference reagents
Women, communities and health systems	Capacity	<ul style="list-style-type: none"> • Identify barriers to access, availability, use and readiness of reproductive services, including contraception and services for discontinuation of pregnancies
	Qualitative	<ul style="list-style-type: none"> • To determine the needs, attitudes and practices of women, men and health care professionals towards pregnancy prevention, abortion, pregnancy care and care for affected children • Community-level operational research by partners, including surveys of knowledge, attitudes and perceptions among people affected by complications associated with ZIKV

Standardized research protocols

WHO is preparing standardized protocols for research on public health questions associated with ZIKV (18). These protocols are available at <http://www.who.int/reproductivehealth/zika/en/>. They should be adapted to the local systems and infrastructure in the setting which the research will be done.

Implementation research

In addition to the priorities listed above, implementation research is required on how interventions can improve the outcomes of people affected by complications associated with ZIKV. For example, research could improve understanding of how interventions for child development could improve the outcomes of children with or at risk for CZVS. **Annex 11** lists specific public health questions on complications associated with ZIKV that could be answered by implementation research.

Planning for research

Every country has its priorities for research, depending on the context, the needs and the resources available. The following points should be integrated into each country's plan for scaling-up research on complications associated with ZIKV.

- Establish mechanisms for collaboration among all national and international stakeholders in research, including academic institutions and centres of excellence. The network should identify country-specific research priorities.
- Establish clear protocols for safe, ethical data-sharing locally, nationally and internationally to promote collaboration.
- Identify capacity building needs, including training and supervision for researchers.
- Ensure adequate funding for capacity building and research.
- Advocate for public support and funding of research.
- Establish mechanisms to ensure that information is shared among researchers and all stakeholders, including affected people, the government decision-makers, public health planners and managers, health care professionals and community workers.

- Strengthen relationships and communication among decision-makers and research institutions to promote use of evidence to inform health policy and improve the performance of health systems.

Knowledge exchange and use of research findings

One of the most important functions of research is to provide evidence to improve the quality and efficiency of services for people affected by ZIKV infection and its complications. To achieve this, public health planners and managers should ensure exchanges of findings among national, regional and international institutions and promote use of the findings of research.

“Knowledge exchange” is the exchange of ideas, evidence and expertise among academics, innovators, users of research and wider groups and communities at both national and international levels. These methods allow sharing, replicating and scaling-up information on effective actions in the field of ZIKV and its complications.

“Research uptake” covers all activities that facilitate and contribute to the use of evidence by policy-makers, practitioners and others working in development. Research uptake can be enhanced by improving the communication and dissemination of results, advocacy and wide stakeholder engagement.

Ethics

Research on people with complications associated with ZIKV must meet ethical standards. The complexity of the situation requires close attention to ensure that research is conducted ethically.

- Research in emergency settings (19, 20): Ethical approval must be obtained for emergency research that involves human participants before the study is begun, and a desire to accelerate research should not obviate a thorough ethics review. Ethics review committees must accelerate their reviews in emergency situations while ensuring a rigorous, peer-reviewed procedure. National and international ethics guidelines for research involving human participants also

apply to all research conducted during emergencies. Accordingly, informed consent must be obtained for research in emergencies involving human participants or their identifiable samples or information.

- Research on pregnant women and their infants (20): The potential effects of ZIKV infection on pregnant women and their infants raise particular ethical and regulatory issues for research. Research with pregnant women is ethically acceptable and should be promoted, because it is critical for ensuring that pregnant women are given safe, effective medical treatment that is essential for their own health and that of their offspring. This is true in both routine and emergency situations.
- Research on children born with or at risk for CZVS (21): Consideration must be given to the purpose of the research and the potential harm and possible benefits of participating in research. Consent must be obtained from the

caregivers of children with or at risk for CZVS. Consent must be given voluntarily and be renegotiable, so that children may be withdrawn from the research at any time. The privacy and confidentiality of the children and families participating in research must be respected. Children with or at risk for CZVS and their families should be properly acknowledged, adequately recompensed and given a fair return for their involvement in research, without coercion or bribery.

- Research on individuals with GBS and other neurological disorders (22): Researchers conducting studies with people with GBS or another neurological disorder should respect their right to choose to participate, their privacy and confidentiality. The role of research subjects should be respected and accommodated, for example by choosing accessible venues for focus group discussions or by finding alternative forms of communication.

LINKS TO RELEVANT RESOURCES

WHO Zika virus research agenda. Geneva: World Health Organization; 2016:

<http://www.who.int/reproductivehealth/zika/zika-virus-research-agenda/en/>.

WHO Zika virus standardized research protocols: Geneva: World Health Organization; 2017:

<http://www.who.int/reproductivehealth/zika/en/>.

Knowledge exchange strategy 2014–2017. Geneva: World Health Organization, Mental Health Innovation Network; 2014: <http://www.mhinnovation.net/resources/mhin-knowledge-exchange-strategy-2014-2017>

Alliance for Health Systems Policy and Systems Research. Geneva: World Health Organization; 2017:

<http://www.who.int/alliance-hpsr/en/>.

Implementation research toolkit. Geneva: TDR; 2017: <http://www.who.int/tdr/publications/topics/ir-toolkit/en/>.

Guidance for managing ethical issues in infectious disease outbreaks. Geneva: World Health Organization; 2016: <http://apps.who.int/iris/handle/10665/250580>

Zika ethics consultation: ethics guidance on keys issues raised by the outbreak. Washington DC: WHO Regional Office for the Americas; 2016: <http://apps.who.int/iris/handle/10665/250580>

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2. Building back better: sustainable mental health care after emergencies. Geneva: World Health Organization; 2013.
3. Mental health gap action programme (mhGAP) intervention guide, version 2.0. Geneva: World Health Organization, Department of Mental Health and Substance Abuse; 2016.
4. Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial Support in Emergency Settings, Inter-Agency Referral Form and Guidance Note, IASC, Geneva, 2016.
5. A socio-economic impact assessment of the Zika virus in Latin America and the Caribbean: with a focus on Brazil, Colombia and Suriname. Vienna: United Nations Development Programme; 2017.
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12. Improving access to and appropriate use of medicines for mental disorders. Geneva: World Health Organization and Calouste Gulbenkian Foundation; 2016.
13. Sejvar JJ, Kohl KS, Gidudu J, Amato A, Bakshi N, Baxter R, et al. Guillain-Barré syndrome and Fisher syndrome: case definitions and guidelines for collection, analysis, and presentation of immunization safety data. *Vaccine* 2011;29:599–612.
14. Potential use of the polio surveillance system for the detection of Zika virus outbreaks. Geneva: World Health Organization; 2017 (<http://www.who.int/emergencies/zika-virus/articles/polio-surveillance/en/>).
15. Craig AT, Butler MT, Pastore R, Paterson BJ, Durrheim DN. Acute flaccid paralysis incidence and Zika virus surveillance, Pacific islands. *Bull World Health Org* 2017;95:69–75.
16. Dirlikov E, Major CG, Mayshack M, Medina N, Matos D, Ryff KR, et al. Guillain-Barré syndrome during ongoing Zika virus transmission – Puerto Rico, January 1–July 31, 2016. *Morb Mortal Wkly Rep* 2016;65:910–914.
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18. WHO Zika virus research agenda. Geneva: World Health Organization; 2016 (<http://www.who.int/reproductivehealth/zika/zika-virus-research-agenda/en/>).
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21. Graham A, Powell M, Taylor N, Anderson D, Fitzgerald R. Ethical research involving children. Florence: UNICEF Office of Research – Innocenti; 2013.
22. Ethical guidance for research with people with disabilities (Disability Research Series). Dublin: National Disability Authority; 2009.

ANNEX 1. ACTIONS FOR STRENGTHENING SYSTEMS TO ENHANCE CARE AND SUPPORT FOR PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS

Care and support	Action
Empowering and engaging people	<ul style="list-style-type: none"> • Train health care professionals and community workers. • Create inclusive environments for affected people. • Set up support groups for affected people. • Conduct effective advocacy. • Include community stakeholders in planning and decision-making.
Coordinating services within and among sectors	<ul style="list-style-type: none"> • Establish care pathway for affected people. • Ensure referral systems between levels of care, including follow-up care in the community. • Establish and coordinate intersectoral and intrasectoral partnerships (e.g. health, social, education)
Reorienting the model of care	<ul style="list-style-type: none"> • Provide care and support for affected people in primary health care, supported by specialist services when available • Ensure essential medicines in primary health care. • Ensure access to mobility devices and assistive equipment. • Ensure access to diagnostic technology and laboratories. • Ensure access to multidisciplinary care. • Ensure access to comprehensive testing and management (e.g. ear and vision). • Integrate surveillance of complications associated with ZIKV into existing surveillance systems.
Strengthening governance and accountability	<ul style="list-style-type: none"> • Ensure that policies and plans integrate the needs of affected people. • Ensure legislation consistent with internationally agreed standards of human rights to provide the needs of affected people. • Ensure resource allocation. • Set up a system for participation of all stakeholders, especially affected people. • Monitor and evaluate care and support for affected people.
Creating an enabling environment	<ul style="list-style-type: none"> • Ensure leadership to manage the integration of care and support (e.g. stakeholder group) for affected people. • Update the information system with core indicators, collected data and reports on complications associated with ZIKV. • Draw up a workforce plan, with task sharing and training for general health care professionals to provide care and support for people affected by complications associated with ZIKV. • Include coverage of CZVS, GBS and other neurological disorders in national health insurance.

ANNEX 2. SAMPLE REFERRAL FORMⁱⁱⁱ

Referring Agency	
Agency / Org:	Contact:
Phone:	E-mail:
Location:	
Referring Agency	
Agency / Org:	Contact (if known):
Phone:	E-mail:
Location:	

ⁱⁱⁱ Copies of a referral form can be used by referring agencies, by receiving agencies and also by clients for their own records.

Client Information

Name:	Phone:
Address:	Age:
Sex:	Nationality:
Language:	ID Number:

If Client Is a Minor (under 18 years)

Name of primary caregiver:	Relationship to child:
Contact information for caregiver:	Is child separated or unaccompanied? <input type="checkbox"/> Yes <input type="checkbox"/> No
Caregiver is informed of referral? <input type="checkbox"/> Yes <input type="checkbox"/> No (If no, explain)	

Background Information/Reason for Referral: (problem description, duration, frequency, etc.) and Services Already Provided

Has the client been informed of the referral? <input type="checkbox"/> Yes <input type="checkbox"/> No (If no, explain below)	Has the client been referred to any other organizations? <input type="checkbox"/> Yes <input type="checkbox"/> No (If yes, explain below)
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Services Requested

<input type="checkbox"/> Mental Health Services	<input type="checkbox"/> Protection Support/ Services	<input type="checkbox"/> Shelter
<input type="checkbox"/> Psychological Interventions	<input type="checkbox"/> Community Centre/ Social Services	<input type="checkbox"/> Material Assistance
<input type="checkbox"/> Physical Health Care	<input type="checkbox"/> Family Tracing Services	<input type="checkbox"/> Nutrition
<input type="checkbox"/> Physical Rehabilitation	<input type="checkbox"/> Legal Assistance	<input type="checkbox"/> Financial Assistance
<input type="checkbox"/> Psychosocial Activities	<input type="checkbox"/> Education	

Please explain any requested services:

Consent to Release Information (Read with client / caregiver and answer any questions before she / he signs)

I, (client name), understand that the purpose of the referral and of disclosing this information to (receiving agency) is to ensure the safety and continuity of care among service providers seeking to serve the client. The service provider, (referring agency), has clearly explained the procedure of the referral to me and has listed the exact information that is to be disclosed. By signing this form, I authorize this exchange of information.

Signature of Responsible Party:

(Client or Caregiver if a minor). Date (DD/MM/YY):

Details of Referral

Any contact or other restrictions? Yes No (If yes, explain below)

Referral delivered via: Phone (emergency only) E-mail Electronically (e.g., App or database) In Person

Follow-up expected via: Phone E-mail In Person. By date (DD/MM/YY):

Information agencies agree to exchange in follow up:
Name and signature of recipient: Date received (DD/MM/YY):

Source: Inter-Agency Standing Committee (IASC) Reference Group for Mental Health and Psychosocial Support in Emergency Settings, Inter-Agency Referral Form and Guidance Note, IASC, Geneva, 2016.

ANNEX 3. CONDUCTING A SITUATION ANALYSIS

Information collection

Information can be collected from secondary or primary sources. Consider collecting information only when it has not previously been collected or is not available in other documents, such as:

- recent situation analyses and assessments;
- national and regional government reports;
- service or regional reports or surveys;
- official government policies, plans and legislation;
- research reports (published or unpublished);
- from WHO, United Nations and other organizations;

- routinely collected information, including clinical information, medical histories, vital status, discharge status or socio-demographic information collected in government censuses or surveys.

Examples of sources of previously collected information and other documents are listed in **Table A3.1**.

WHO MiNDbank (<https://www.mindbank.info>) (**Box A3.1**) is an online platform for sharing national and international resources related to mental health, substance abuse, disability, general health, human rights and development. It can be a useful source of information for a situation analysis.

TABLE A3.1. EXAMPLES OF SOURCES OF PREVIOUSLY COLLECTED INFORMATION AND DOCUMENTS

Specialty	Examples of documents
Neurology	Epilepsy legislation WHO. Assessment instrument for mental health systems (country reports) WHO. Atlas: Epilepsy care in the world 2005 WHO. Neurological disorders: Public health challenges
Mental health and psychosocial Support	Mental health policies, plans and legislation WHO. Mental health atlas 2014 (country profiles) WHO. Assessment instrument for mental health systems (country reports)
Rehabilitation and disability	Disability legislation Rehabilitation policies and plans WHO. World report on disability 2011
Vision and eye care	Eye care policies, plans and legislation
Hearing and ear care	WHO. Multi-country assessment of national capacity to provide hearing care
Nutrition	International Food Policy Research Institute. Global nutrition report: From promise to impact: Ending malnutrition by 2030 (country profiles)
Laboratory services	WHO. World health statistics 2017: Monitoring health for the SDGs
Child and maternal health	Policies and plans for developmental screening UNICEF. Countdown to 2015 (country reports) WHO. Maternal and perinatal health (country profiles)
Primary care	WHO. World health report 2008: primary health care (Now more than ever)
Human resources	WHO. Human resources for health (country profiles)
Reproductive health	Reproductive health policies, plans and legislation
Public health	Public health policies, plans and legislation
Sanitation	Sanitation policies, plans and legislation

Methods of collecting information

From clinics and facilities: Information collected from clinics and facilities indicates the patterns and standards of treatment and care, the clinical workflow and referral systems. This type of information does not provide generalizable information about the underlying general population.

Key informants or expert opinion: When possible, use key informants or experts to find more generalizable sources of data such as those listed in **Box A3.1**. When generalizable sources are not available, opinions can be solicited from key informants or experts; such sources should be explicitly identified, as caution is required in interpreting opinions. Information may be collected in narrative interviews or by free listing. Key informants and experts should include not only specialists such as neurologists but also people affected by complications associated with ZIKV and community leaders. **Box A3.2** describes interviewing techniques.

Qualitative data: These are derived from individual or group interviews (e.g. focus groups) and are used to understand a narrow topic in greater depth than can be obtained with a broad survey. Focus groups are well suited for understanding the cultural context of stigma, traditional beliefs and customs underlying health-seeking behaviour and barriers to seeking treatment.

From the population: If adequate resources are available, a comprehensive door-to-door survey will provide the most generalizable, representative data on the general population. Surveys are ideal for estimating treatment gaps in the community, the knowledge, attitudes and practices of the general population, attitudes towards stigma and the number of people who do not or are unable to access health or social care systems.

BOX A3.1. MiNDbank

- national mental health policies, strategies and laws;
- national disability policies, strategies and laws;
- national general health policies, strategies and laws;
- national noncommunicable diseases policies and strategies;
- national alcohol and substance abuse policies, strategies and laws;
- national general, mental health, health, disability and substance abuse policies, strategies and laws for young people;
- national mental health, health, disability and substance abuse policies, strategies and laws for older people;
- national standards for mental and general health services for children, young people and older people;
- evaluations of policies, strategies, laws and services for mental health, disability, general health, substance abuse for children, young people and older people;
- national constitutions and laws on human rights and children's rights;
- national poverty reduction and development strategies;
- international and regional human rights conventions and treaties;
- the United Nations Convention on the Rights of Persons with Disabilities: Member States reports, list of Issues, shadow reports and concluding observations;
- United Nations Special Rapporteur's reports;
- WHO resources; and
- United Nations and WHO resolutions.

Priority of data sources

More recent data are preferred to older data. Data from the country that are more recent than those in other sources (e.g. WHO, United Nations, World Bank) take precedence; however, in situations of constrained resources, use of secondary data may be preferable to undertaking primary data collection. A balance must be struck between resources for situation analyses, feasibility and recency.

Data that can be generalized or are representative take precedence over data on a convenience sample of a selected group (e.g. key informants, opinion leaders). When possible, data from studies or sources that allow the greatest generalizability or are most representative are to be preferred. In general, key informants should be the last resort for obtaining data.

Example outline of a situation analysis report related to complications associated with ZIKV

- 1.** Contextual background
- 2.** Health and social background, including prevalence and treatment gaps (in e.g. neurology, mental health, rehabilitation)
- 3.** Current capacity of health and social infrastructure and systems
- 4.** Current capacity in terms of human resources
- 5.** Community resources available
- 6.** Recommendations for enhancing care and support, listed in order of priority
- 7.** Barriers to enhancing care and support and suggested solutions
- 8.** Conclusion (synthesize all information)

BOX A3.2. TIPS FOR GOOD INTERVIEWING

Be familiar with the information you want to collect before you conduct an assessment. This will make you more confident and at ease.

Interviewer's attitude

- Be warm and understanding towards the person you are interviewing. Thus, show the person that you are listening, and responding to what they say. You can say things like "That's great!", "I'm sorry!", "That's a shame!" or "I see!" to let the person know that you are listening and that you care about their situation. Be careful, however, not to make them believe that you will be able to help them.
- Let the person give you his or her opinion fully.
- It is sometimes useful to repeat the person's answers to them in your own words before making a rating, to make sure that you understood them correctly. For example, you could say: "So, have I understood you correctly? Are you saying...?" This also shows the person that you are listening.
- The people you are interviewing may be angry or upset about their situation. Be understanding and kind.

Verbal skills

- Speak slowly and clearly to make sure that the person understands you.
- Use a pleasant, friendly tone.
- Leave pauses and silences between questions to give the person an opportunity to think about his or her answers and give you an opinion.

Phrasing questions

- Make your questions simple and clear.
- If the person does not give you a clear answer, try phrasing the question differently.
- You may check with the person if their answer is not clear.

Handling diversions

- If the person gives very long or irrelevant answers, you could say something like: "That is very interesting. However, I have many more questions to ask, so could we please move on to those?", or "We can talk about that some more after the interview, if you would like to."
- If the person asks for advice, information or your personal experiences, you could say: "We are really interested in finding out about your experiences and perceptions." or "We can talk about that after the interview."



Handling distress

- If the person gets upset at any point during the assessment, slow down or take a short break. Ask the person whether he or she can continue the interview, and stop the interview if asked.
- Do not keep asking questions or challenge the person too much about sensitive or difficult subjects. If the person becomes very upset by a topic, you could put down your notes and wait until he or she calms down. You could then say: "You seem very upset. Do you want to continue the interview, or would you prefer to stop?"
- Remember that a person can choose not to answer a question if he or she does not want to.

ANNEX 4. TEMPLATE FOR IDENTIFYING AND PRIORITIZING ACTIONS

	Action	Relevance to the context (Why)	Location (Where)	Resources needed (What)
Women and girls of childbearing age				
Children born with CZVS				
People with GBS and other neurological complications				
Other				
Surveillance				
Research				

Steps

1. Identify an adaptation task force within the stakeholder group.
 - Include local experts in all aspects of multidisciplinary care.
 - Include senior leaders in health and social care to encourage acceptance of the proposed adaptation and to ensure final endorsement of the guidelines by the heads of the health and social welfare ministries.
2. Prepare and review relevant documents:
 - WHO toolkit for the care and support of people affected by complications associated with Zika virus infection:
 - Manual for health care professionals and
 - Manual for community workers;
 - requirements for mainstreaming care and support in health care settings (see section 1.3);  1.3
 - completed situation analysis (see section 2.2);  2.2
 - previously collected information and other documents to inform the situation analysis, such as national policies, plans and legislation (**Annex 3**); and
 - the completed action plan (**Annex 4**)
3. Use the adaptation guide form.
4. Identify experts from relevant disciplines (e.g. psychiatry, neurology, paediatrics, rehabilitation, social work) and collect their suggestions on the adaptation by, for example, sharing the document by e-mail or organizing a one-day meeting.
5. Discuss the suggested adaptations with the adaptation task force.
6. Make the adaptations, and disseminate the updated training packages to relevant stakeholders.

Tips

- Ensure that the adaptations are in line with national documents (e.g. the national health policy, legislation and plan, clinical protocols and guidelines in general and primary health care and the national medicines list).
- Encourage the members of the adaptation task force and the experts consulted to familiarize themselves with the Toolkit before working on the document. This will give inform them about the rationale, purpose, content and the intended audience of the generic version of the package.
- Some countries might have already conducted adaptation, and it might be useful to consider adaptations that have been made in other contexts.
- Do not change for the sake of change; make only essential adaptations to the training materials.
- Discuss and document the reasons and technical basis for changes.

ANNEX 6. TEMPLATE FOR PLANNING CAPACITY BUILDING

	Training of facilitators and supervisors	Health care professionals	Community workers
Training			
Who will be responsible for planning and conducting training, including the schedule?			
Who will be trained?		All health care professionals or a sub-set?	All community workers or a sub-set?
Who will adapt the training materials to the context?			
Who will be master facilitators?			
Who will be facilitators?			
Supervision and support			
Who will be responsible for planning and conducting supervision and for setting a supervision schedule?			
Who will be the supervisors?			
How can supervisors be trained to do their job properly?			
What plans are required for supervision and support?			
How will the trained personnel be motivated and realistically have the resources (e.g. time, equipment, medication) to use their new skills?			
How can facilitators and supervisors reinforce established referral mechanisms and good practice in collaborative, multi-disciplinary person-centred care and referral systems?			

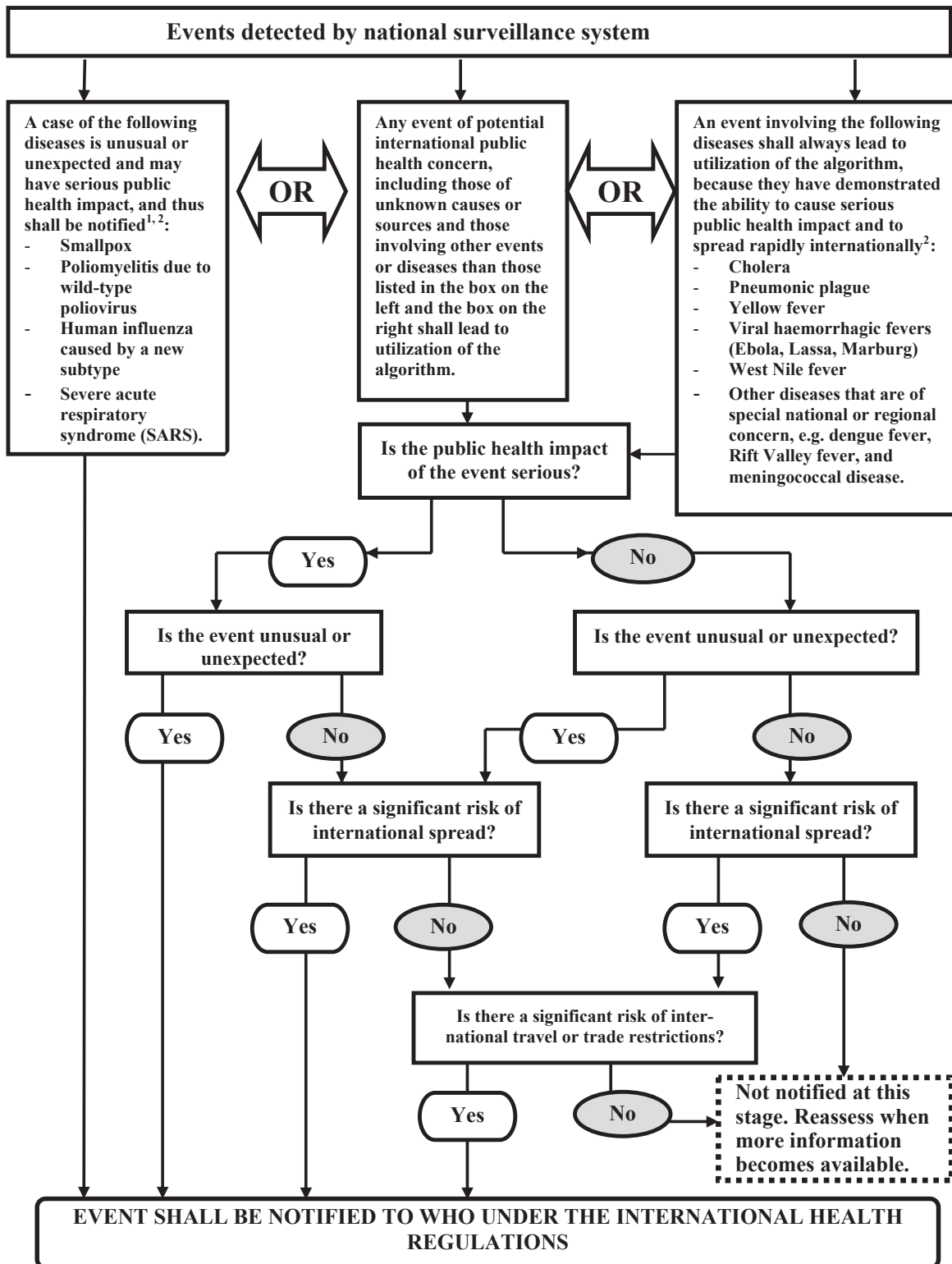
ANNEX 7. TRAINING AND SUPERVISION CHECKLISTS

Task	Completed
Initial planning	
Dates <ul style="list-style-type: none"> • Dates for training of facilitators and supervisors selected • Dates for training health care professionals selected • Dates for training community workers selected 	
Course materials <ul style="list-style-type: none"> • Adapted to context • Printed (one for each participant) • Note pad and ball-point pen for each participant • Other 	
Logistics <ul style="list-style-type: none"> • Venue (e.g. seating, microphones, no noise, Internet access) • Presentation materials (e.g. projector, computer, flipcharts, pens, paper) • Food and catering • Transport • Budget • Other 	

Task	Completed
Preparation for training of facilitators and supervisors	
Master facilitators selected	
Future facilitators nominated and invited (include any background reading with invitations)	
Locations and rooms reserved and communicated to participants	
Book interpreter if relevant	
Arrangements for per diem, accommodation, transport, etc.	
Master facilitator • Presentation slides • Hand-outs	
Materials for participants	
Preparation for training of health care professionals and community workers	
Facilitators selected (If the supervisors are not the facilitators, also identify supervisors.)	
Letters sent to appropriate district, regional or local office asking the office to identify appropriate participants	
List of nominated health care professionals and community workers compiled	
Letters of invitation sent to nominated participants	
Locations of classrooms and lodging confirmed	
Arrangements made for printing and transporting course materials	
Arrangements made for providing per diem	
At the course location, before training (including training of facilitators and supervisors), a few days before training	
Locations and rooms reserved and communicated to participants	
Lodging confirmed	
Transport confirmed	
Workshop rooms confirmed	
Training materials and supplies organized	
Course directory (name and affiliation of each participant, facilitator and planner) for registration prepared	
Use of a photocopier and printer during the course arranged	
Coffee, tea and lunch arranged	
Opening address planned	
During the course	
Course participants registered	
Course directory provided to everyone	
Pre-test and post-test data collected	
Daily evaluation forms completed	
Course completion certificate prepared for each participant and presented at end of course	
Plans for supervision and follow-up visits finalized and announced at the closing session	

Complete supervision planning checklist	
Task	Completed
Initial planning	
Dates for supervision selected	
Lists of trainees provided to each facilitator	
Logistics • Transport • Budget • Other	

ANNEX 8. INSTRUMENT FOR ASSESSING AND NOTIFYING EVENTS THAT MAY CONSTITUTE A PUBLIC HEALTH EMERGENCY OF INTERNATIONAL CONCERN



¹ As per WHO case definitions.

² The disease list shall be used only for the purposes of these Regulations.

ANNEX 9. FORM FOR REPORTING MICROCEPHALY AND OTHER NEUROLOGICAL CONDITIONS THAT MAY BE ASSOCIATED WITH ZIKA VIRUS

Reporting Form	
Unique ID (XXX-YYY-000)	
Date of report (dd/mm/yy)	
Submitted by (SURNAME NAME)	
Contact number (Incl. country code)	
Contact email	
WHO regional office	<input type="checkbox"/> AFRO <input type="checkbox"/> AMRO <input type="checkbox"/> EMRO <input type="checkbox"/> EURO <input type="checkbox"/> SEARO <input type="checkbox"/> WPRO
Country/territory/area of report	
First admin level below national level of report (eg. province)	
Country/territory/area of Zika infection in the mother	
First admin level below national level of Zika infection in the mother (eg. province)	
Confirmation of microcephaly	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
If yes, is there any associated congenital malformation	
Specify congenital malformations (whether microcephaly is confirmed or not) (Anencephaly/Encephalocole/Spina Bifida, Hydrocephalus/Other)	<input type="checkbox"/> Anencephaly <input type="checkbox"/> Encephalocole <input type="checkbox"/> Hydrocephalus <input type="checkbox"/> Spina Bifida <input type="checkbox"/> Other <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Diagnosis of microcephaly (in utero/after birth)	<input type="checkbox"/> In utero <input type="checkbox"/> After birth <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Result of neuroimaging in utero	
Result of neuroimaging after birth	
Start date of pregnancy (dd/mm/yy)	
Gestational age of pregnancy (in weeks, if not known, approximation week is required)	
Trimester of pregnancy (if known) (1/2/3)	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Outcome of pregnancy (at time of reporting)	<input type="checkbox"/> Ongoing <input type="checkbox"/> Medical termination <input type="checkbox"/> Miscarriage <input type="checkbox"/> Still birth <input type="checkbox"/> Live birth <input type="checkbox"/> Died shortly after birth <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Head circumference of baby (in cm)	
Standard deviation (WHO Growth Standard for term neonates)	

continued on next page

Reporting Form

Mother

History of Zika virus infection of mother (yes/no)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Source of infection of mother (imported/local/undetermined/unknown)	<input type="checkbox"/> Imported <input type="checkbox"/> Local <input type="checkbox"/> Undetermined <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Was the mother Zika virus laboratory confirmed	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Pending <input type="checkbox"/> Blank
Name of laboratory	
Serology (in house assay/commercial assay)	<input type="checkbox"/> In house assay <input type="checkbox"/> Commercial assay <input type="checkbox"/> Blank
First test IgM positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of first test of IgM positive (dd/mm/yy)	
Paired sample: Second test of IgM positive (yes/no)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Paired sample: Date of second test of IgM positive (dd/mm/yy)	
First test IgG positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of first test of IgG positive (dd/mm/yy)	
Paired sample: Second test of IgG positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Paired sample: Date of second test of IgG positive (dd/mm/yy)	
Positive RT-PCR test	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of positive RT-PCR test (dd/mm/yy)	
Specimen tested (amniotic fluid/blood/urine/ umbilical cord)	<input type="checkbox"/> Amniotic fluid <input type="checkbox"/> Blood <input type="checkbox"/> Umbilical cord <input type="checkbox"/> Urine <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
PRNT: Four-fold rise	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Test to rule out TORCH done on mother	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
If yes, which disease/s tested positive	

Baby

Baby tested for Zika virus	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Baby tested positive IgG	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Baby tested positive IgM	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
RT-PCR test (Baby after birth)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Specimen tested	
Result of RT-PCR test (positive/negative)	<input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Karyotype	

ANNEX 10. FORM FOR REPORTING GUILLAIN BARRÉ SYNDROME AND OTHER NEUROLOGICAL CONDITIONS ASSOCIATED WITH ZIKA VIRUS

Reporting Form	
Unique ID (XXX-YYY-000)	
Date of report (dd/mm/yy)	
Submitted by (SURNAME NAME)	
Contact number (Incl. country code)	
Contact email	
WHO regional office	<input type="checkbox"/> AFRO <input type="checkbox"/> AMRO <input type="checkbox"/> EMRO <input type="checkbox"/> EURO <input type="checkbox"/> SEARO <input type="checkbox"/> WPRO
Country/territory/area of report	
First admin level below national level of report (eg. province)	
Country/territory/area that Zika infection took place	
First admin level below national level that Zika infection took place	
<hr/>	
Date of birth of case (dd/mm/yy)	
Confirmation of Guillain Barré Syndrome	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
If no, other neurologic condition, please specify (Transverse myelitis, Acute Disseminated Encephalomyelitis, Other, Unknown)	<input type="checkbox"/> Transverse myelitis <input type="checkbox"/> Acute Disseminated Encephalomyelitis (ADEM) <input type="checkbox"/> Other <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Acute flaccid paralysis (AFP)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of onset (dd/mm/yy)	
Has the case been hospitalised (yes/no)	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Treatment received (IVC/Plasmapheresis/other)	<input type="checkbox"/> IVC <input type="checkbox"/> Plasmapheresis <input type="checkbox"/> Other <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Admitted in ICU	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Discharged	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of discharge (dd/mm/yy)	
Current status as of date of report	<input type="checkbox"/> Alive <input type="checkbox"/> Dead <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
History of disease compatible with Zika virus	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of previous history of disease compatible with Zika virus	
Was the infection vector-borne	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
If other, please specify (blood-borne/sexual/unknown)	<input type="checkbox"/> Blood-borne transmission <input type="checkbox"/> Sexual transmission <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Source of infection	<input type="checkbox"/> Imported <input type="checkbox"/> Local <input type="checkbox"/> Undetermined <input type="checkbox"/> Unknown
Was Zika virus laboratory confirmed	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Pending <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank

Reporting Form

Serology (in house assay / commercial assay)	<input type="checkbox"/> In house assay <input type="checkbox"/> Commercial assay <input type="checkbox"/> Blank
First test IgM positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of first test of IgM positive (dd/mm/yy)	
Paired sample: Second test of IgM positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Paired sample: Date of second test of IgM positive (dd/mm/yy)	
First test IgG positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of first test of IgG positive (dd/mm/yy)	
Paired sample: Second test of IgG positive	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Paired sample: Date of second test of IgG positive (dd/mm/yy)	
Positive RT-PCR test	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Date of positive RT-PCR test (dd/mm/yy)	
Other tests done to rule out following diseases (Dengue/ Chikungunya / HIV / Campylobacter jejuni / None)	<input type="checkbox"/> Campylobacter jejuni <input type="checkbox"/> Chikungunya <input type="checkbox"/> Dengue <input type="checkbox"/> HIV <input type="checkbox"/> None <input type="checkbox"/> Not applicable <input type="checkbox"/> Unknown <input type="checkbox"/> Blank
Please specify each test carried out	

ANNEX 11. PRIORITIES FOR RESEARCH ON COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS

Discipline	CZVS	GBS
Epidemiology	<ul style="list-style-type: none"> Absolute risk for congenital malformations associated with ZIKV by gestation (week), including incident cases, birth defects; an epidemic curve Factors that modify risk for infection and neurodevelopmental sequelae, e.g. influence of co-infections and super-infections with ZIKV and other co-circulating arboviruses (chikungunya, dengue, yellow fever viruses), pre-existing immunity or vaccination against other flaviviruses Use of modelling to understand the rate of infection and the role of natural immunity, particularly in regions with previous ZIKV outbreaks Spatial distribution of ZIKV, dengue and chikungunya viruses <p>Predictors of severity</p> <ul style="list-style-type: none"> Characterization of clinical and subclinical ZIKV infections in pregnant women Characterization from neuroimaging results Other predictors of adverse outcomes in infants with and without early microcephaly (e.g. clinical assessment tools, other biological markers) Clinical, laboratory and virological parameters of people infected with ZIKV associated with complications or indicators of progression to more severe disease (e.g. viral load) <p>Natural history</p> <ul style="list-style-type: none"> Natural history of the disease; ratio of clinical to subclinical incidence of CZVS and other neurological complications; rare severe complications; mortality; dynamics of immune response CZVS mortality and morbidity, including neurodevelopmental and other systemic outcomes (e.g. other congenital anomalies, feeding and nutrition, respiratory, cardiac anomalies) 	<ul style="list-style-type: none"> Prevalence of ZIKV-associated neurological complications in children and adults Spectrum and prevalence of neurological conditions associated with ZIKV Demographic features (i.e. age, gender, ethnic distribution) of individuals with ZIKV-associated GBS Contribution of axonal and demyelinating damage to the pathophysiology of GBS in the context of ZIKV infection Morbidity and mortality associated with GBS and other neurological complications associated with ZIKV

Discipline	CZVS	GBS
Pathogenesis	<ul style="list-style-type: none"> • Effect of timing of ZIKV infection on developing fetus • Pathogenesis of ZIKV infection in the fetus • Effects of flaviviruses (including viral persistence and viral load) on neural tissues, placental barrier transfer and teratogenicity 	<ul style="list-style-type: none"> • Risk factors for the development of GBS and other neurological complications associated with ZIKV • Role of prior or concurrent infection in the development of neurological complications associated with ZIKV • Biomarkers for ZIKV-associated GBS and other neurological complications
Public health	<ul style="list-style-type: none"> • Registries of congenital birth defects • Impact of public health recommendations • Impact of training of facility and community health providers in ZIKV-affected areas • Feasibility and sustainability of providing comprehensive, integrated care and support through guidelines and training • Adapting models for developmental monitoring of children at risk for or with CZVS, so that they are feasible, appropriate, valid and sustainable at scale in all settings • Ethics of developmental monitoring in settings of high ZIKV prevalence and monitoring for unintended consequences • Adaptation of universal early child development interventions for children with neurodevelopmental difficulties or disabilities due to CZVS • Community-based models of early intervention for children with developmental disabilities due to CZVS (e.g. to improve motor, language and communication, activities of daily living and prevent secondary complications) • Optimal modes of delivery of care in all settings (e.g. facility, community or by group or individual home visits) 	<ul style="list-style-type: none"> • Prevention and risk communication for GBS and other neurological complications associated with ZIKV • Registries of GBS and other neurological complications associated with ZIKV • Impact of public health recommendations for the assessment and management of GBS and other neurological complications in the context of ZIKV
Health systems and services response	<ul style="list-style-type: none"> • Efficient financing mechanisms for addressing outbreaks of ZIKV • Strengthening congenital birth defects surveillance and health information systems to register and monitor long-term complications of CZVS • Mechanisms to ensure the provision of health services for people with complications of ZIKV • Barriers to access and mechanisms to improve inclusiveness of health systems to increase the access of children and families affected by CZVS • Mechanisms to improve integration of child development interventions into routine health services sustainably and at scale • Human resource approaches to improving care and support for children with or at risk for CZVS: cadre (community-based rehabilitation, community workers, parents, “combined therapists”) • Mechanisms for monitoring and supporting the protection of children with CZVS • Integrating health and educational responses for children with CZVS • Monitoring and evaluation frameworks 	<ul style="list-style-type: none"> • Availability of personnel to assess neurological complications • Neurological examination skills of the primary care workforce • Skills of intensive care staff for the management of neurological complications, including GBS • Access to ventilation support equipment and telemetry monitors • Access to lumbar puncture toolkits and training • Access to equipment and training in neurophysiological testing and interpretation • Access to primary, secondary and tertiary care (including intensive care) • Access to psychosocial and family support services to manage GBS and other neurological complications associated with ZIKV • Availability, affordability and access to intravenous immunoglobulin G and therapeutic plasma exchange • Availability, affordability and access to neurorehabilitation

Discipline	GBS	CZVS
Research and development of products	<ul style="list-style-type: none"> • Reliable, accurate, standardized testing for GBS and other neurological conditions associated with ZIKV • Clinical, laboratory and virological parameters in people with ZIKV-associated neurological complications or that predict progression to more severe disease 	<ul style="list-style-type: none"> • Potential antiviral treatment for known infections during pregnancy and for congenital disease • Sensitivity and specificity of ZIKV laboratory diagnostics in infants or children exposed in utero but diagnosed later • Distinction between congenital and neonatal infection and effects on neurodevelopmental outcomes
Broader impact on families and communities		<ul style="list-style-type: none"> • Social impact of CZVS on parents, families and communities in various settings • Psychosocial interventions to improve the outcomes of children and families affected by CZVS • Barriers to and strategies to promote inclusion in various settings • Economic implications for families and communities • Social protection strategies to support the families of children with CZVS in various settings


**WHO TOOLKIT FOR THE CARE AND SUPPORT OF PEOPLE
AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS**

Manual for public health planners and managers

This manual is designed for experts who develop and carry out public health programmes involved in the continuing response to Zika virus, its complications and the consequences for countries and regions. The manual outlines the main considerations in mainstreaming services for people affected by complications associated with Zika virus and the concrete steps to be taken to enhance care and support.

The manual contains the following modules:

1. Essential information on complications associated with Zika virus
2. Strengthening the long-term response to Zika virus

For practical guidance on providing care and support to people affected by complications associated with Zika virus, refer to the Manual for health care professionals and the Manual for community workers. 

**WHO TOOLKIT FOR THE CARE AND SUPPORT
OF PEOPLE AFFECTED BY COMPLICATIONS
ASSOCIATED WITH ZIKA VIRUS**

Manual for health care professionals



**World Health
Organization**





This manual aims to build capacity for the delivery of care and support in Zika virus-affected areas, with a focus on child health care, neurological care and mental health and psychosocial support. The target readership of the manual is non-specialist health care professionals who meet the needs of people affected by complications associated with Zika virus, both children and adults, as well as their caregivers and families.¹ The manual is designed for health care professionals in facilities with a basic health workforce, general medications and access to diagnostic facilities and specialty care (either on site or by referral). Health care professionals at facilities should coordinate with community workers in delivering comprehensive care and support.

¹ Throughout this manual, the terms “caregiver” and “family” are used to refer to the primary sources of care and support for people affected by complications associated with ZIKV. They include both formal and informal caregivers in the community. Families are an important unit in the care and support of both children and adults affected by complications associated with ZIKV. The constitution of a family may differ by context, comprising not only parents or partners but also siblings, grandparents and extended family members.

MODULE 1

Management of children born in Zika virus-affected areas

- 1.1 *Supportive communication*
- 1.2 *Antenatal guidance for pregnant women in Zika virus-affected areas*
- 1.3 *Assessment and management of congenital Zika virus syndrome*

MODULE 2

Assessment and management of people with Guillain Barré syndrome and other neurological complications triggered by Zika virus

- 2.1 *Introduction*
- 2.2 *Supportive communication*
- 2.3 *Assessment of people with Guillain Barré syndrome in the context of Zika virus*
- 2.4 *Management of Guillain Barré syndrome triggered by Zika virus*

MODULE 3

Mental health and psychosocial support for people affected by complications associated with Zika virus

- 3.1 *Common reactions and assessment of mental health and psychosocial needs*
- 3.2 *Psychosocial interventions*
- 3.3 *Management of severe conditions*
- 3.4 *Specific considerations for people with Guillain Barré syndrome*

1

MODULE

Management of children born in Zika virus-affected areas

The aim of this module is to provide practical guidance for the diagnosis of congenital Zika virus syndrome and management of children with and at risk for the condition.

- 1.1 *Supportive communication*
- 1.2 *Antenatal guidance for pregnant women in Zika virus-affected areas*
- 1.3 *Assessment and management of congenital Zika virus syndrome*

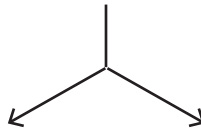
ASSESSMENT AND MANAGEMENT OF CONGENITAL ZIKA VIRUS SYNDROME (CZVS)



Provide appropriate antenatal care

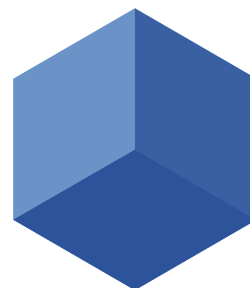


Initial assessment for CZVS at health care facility at birth (see Fig. 1)



Protocol for confirmed or probable CZVS:

- Follow-up at 2 weeks, 3 months, 6 months, 9 months, 12 months, 18 months and 24 months at a minimum
- Detailed assessment of growth, neurodevelopment, hearing, vision and known complications (e.g. spasticity, seizures, feeding problems) at each visit. *(See Table 1 for detailed guidance).*






Routine monitoring of signs and symptoms that may appear later in infancy:

- Close developmental monitoring recommended at minimum visits
- Vision and hearing, including a physiological hearing test at least once before the age of 2 years.
- In case of deceleration of head growth or neurodevelopmental abnormalities with no identified etiology, re-investigation for ZIKV and re-evaluation of the child at a health facility are recommended.


TABLE 1. PROTOCOL FOR MANAGEMENT OF CONGENITAL ZIKA VIRUS SYNDROME


Neurodevelopmental Evaluation			
	Key considerations	Vision Assessment (1,2)	Hearing Assessment (3)
Initial visit (within first 2 weeks of life)	<ul style="list-style-type: none"> Measure head circumference, length and weight; interpret measurements against WHO child growth standards. Evaluate ability to feed. Evaluate tone. Take a history assessing for seizures. 	<ul style="list-style-type: none"> Perform external examination for structural abnormalities Assess reaction to light and faces. Check pupillary response for any irregularity or asymmetry of pupils. Assess red reflex response in each eye, noting abnormalities, including dark spots in the red reflex or a white reflex. 	<ul style="list-style-type: none"> Behavioural evaluation: infant should show some sign of hearing sounds, e.g. open eyes, blink, look alert. If available, a physiological hearing screen [automated auditory brainstem response (AABR) or otoacoustic emissions (OAE)] should be performed, if not done at birth.
3 months	<ul style="list-style-type: none"> Measure head circumference, length and weight; interpret measurements against WHO child growth standards. Perform a developmental screen with culturally validated tools, if available. Evaluate ability to feed. Evaluate tone, in particular for spasticity, delayed motor milestones and development of contractures. 	<ul style="list-style-type: none"> Assess for ability to fix and follow objects and follow an adult located about 50 cm away. An ophthalmological evaluation should be performed, if available. 	
6 months	<ul style="list-style-type: none"> Take a history assessing for seizures or abnormal movements, specifically for spasms 	<ul style="list-style-type: none"> Ask caregivers and families whether the child's vision appears normal or whether they have observed any abnormal eye movements or alignment. 	<ul style="list-style-type: none"> Behavioural evaluation: infants should respond by trying to see where a sound is coming from by turning their head or eyes in the direction of the sound.
9 months	<ul style="list-style-type: none"> Provide routine vaccination as per schedule. 	<ul style="list-style-type: none"> Screen at each visit for ability to fix and follow objects, any apparent impairment of vision or abnormal eye movements. Check reaction to contrast, light, colour and shapes to determine any apparent deficit in visual acuity, behaviour or fixation pattern. 	<ul style="list-style-type: none"> Behavioural evaluation: infants should be listening to loud and very soft sounds and making many different sounds themselves. Repeat hearing test (AABR or OAE)
12 months	<ul style="list-style-type: none"> Measure head circumference, length and weight; interpret measurements against child growth standards. Perform a developmental screen with culturally validated tools, if available. Evaluate ability to feed. 	<ul style="list-style-type: none"> Check for any abnormality of visual axis alignment (e.g. strabismus) by having the child focus on a light, which should be reflected in the centre of each pupil, or use a cover-uncover test. 	<ul style="list-style-type: none"> Behavioural evaluation: Children should respond to their names and to words.
18 months	<ul style="list-style-type: none"> Evaluate tone, in particular for spasticity, delayed motor milestones, development of contractures and whether assistive devices would be helpful. 	<ul style="list-style-type: none"> Check for any abnormal eye movements (e.g. nystagmus). 	<ul style="list-style-type: none"> Behavioural evaluation: Children should be able to point to familiar things when asked to do so and use simple words. Repeat hearing test (AABR or OAE).
24 months	<ul style="list-style-type: none"> Take a history assessing for seizures or abnormal movements. Provide routine vaccinations as per schedule. 		<ul style="list-style-type: none"> Behavioural evaluation: Ask caregivers and family members whether the child appears to hear normally even when spoken to very softly; assess whether the child has appropriate language development (e.g. starting to put together words and a vocabulary of > 10 single words at a minimum).


Neurodevelopmental Management


- A multidisciplinary care team should be formed of the relevant specialists and community workers.
- Caregivers, families and community workers should be trained in promoting child development and, when appropriate, providing more targeted support for daily functioning (e.g. basic physiotherapy and interventions to enhance learning, play and communication).
- Caregivers and families should be trained to recognize potential complications, including seizures.
- In developmental support programmes, it should be recognized that children with CZVS often have hearing and vision impairments and should accommodate for this possibility.
- Provide nutritional support for poor weight gain or feeding problems.
- Provide guidance for possible aspiration in feeding difficulties, including keeping the child upright during feeds and thickening food, if appropriate.
- For any abnormality on functional visual assessment, refer to an ophthalmologist.*
- If infant fails behavioural hearing assessment, refer for OAE or AABR.
 AABR should be performed when available and if strong clinical suspicion exists or if OAE is failed. Children with confirmed hearing impairment should be referred for appropriate hearing aids when available.
- Abnormal tone should be managed by physiotherapy, assistive devices for contractures, as necessary, and medication for spasticity as necessary.
- If seizures or spasms occur, acute seizure management should be used as per WHO guidelines, with referral to paediatric neurology and an electroencephalogram (EEG),  if possible (4, 5).

Mental Health and Psychosocial Support for Caregivers and Families

- Provide empathetic, supportive communication about the diagnosis and expected needs, including rehabilitation, close medical monitoring, developmental prognosis and complications, including potential feeding problems and seizures.
- Support the caregiver and families in stress management, when appropriate.
- If available, provide information on caregiver and family support groups and other resources.
- Caregivers and family members who show signs of severe distress that affect their social or occupational functioning should be referred to a mental health care provider. 

- Encourage interaction with the child, emphasizing the importance of environmental stimulation for optimal development.
- Continue to support the caregiver and family in stress management, when appropriate, and encourage the caregiver to take periods of respite.
- Caregivers and family members, who show signs of severe distress, affecting their social or occupational functioning, should be referred to a mental health care provider. 

- Discuss plans for preschool and the services that will be required in school; connect family with available resources.
- Continue to support the parent or caregiver in stress management, when appropriate, and encourage the caregiver to take periods of respite.
- Parents and caregivers, who show signs of severe distress, affecting their social or occupational functioning, should be referred to a mental health care provider. 

*Throughout the text, presentations that should trigger referral are indicated by 



Supportive Communication

Expectant parents in Zika virus (ZIKV)-affected areas may feel frightened and uncertain, and, for those whose children are born with CZVS, the news is distressing at multiple levels. The medical complications are often overwhelming, and the ensuing financial strain and, in many communities, stigma of a child with disabilities, particularly those associated with ZIKV, can be devastating to caregivers and families. Sometimes, partners leave after the birth of an affected child, compounding the difficulties.

Understanding good strategies for supportive communication is essential for delivering comprehensive care and support.

LEARNING OBJECTIVES

- ➔ *Recognize that all pregnant women in ZIKV-affected areas may be very afraid and distressed about their pregnancy due to concern about CZVS.*
- ➔ *Be aware of the ethical obligations and national laws that are relevant to expectant mothers.*
- ➔ *Provide support and empathy effectively, without judgement.*
- ➔ *Inform caregivers and families of children with CZVS about possible complications, while maintaining hope and giving encouragement.*

General tips on communication (6)

● **Create an environment that facilitates open communication:**

- Be welcoming, and introduce yourself in a culturally appropriate manner.
- When possible, find a quiet, private space with minimal distractions where people can share their feelings and concerns.
- Do not interrupt or rush people while they are speaking (e.g. avoid speaking rapidly or looking at your watch).
- Explain that whatever is said will be kept confidential.
- Maintain eye contact and use body language and facial expressions that engender trust.

● **Listen:**

- Remember that people affected by ZIKV may feel confused, upset, angry and frightened.
- Use simple language, and stay calm, even when caregivers and families are acutely distressed, allowing them to feel respected and empowered.
- Acknowledge their feelings (e.g. "I'm so sorry. I can imagine it must be very sad for you."), and reassure them that stress and grief are common reactions in such difficult situations.
- Do not judge their feelings; avoid saying "You should not feel that way".
- Acknowledge the positive coping mechanisms and methods that they use to reduce stress.
- Allow periods of silence.

● **Be respectful and supportive and provide accurate information:**

- Provide non-judgemental advice against negative coping mechanisms, especially those with adverse effects on the person, caregiver and family.
- Be sensitive to cultural differences and perceptions; be aware of and set aside your own biases and prejudices.
- Give caregivers and families accurate, up-to-date sources of information.

● **Deliver information clearly:**

- Use non-technical language.
- Encourage questions.
- Summarize and repeat key points.

● **Recognize your own needs:**

- When you need it, take a break until you can effectively provide supportive communication.

Additional tips and ethical considerations with regard to pregnant women (7)

- Pregnant women should be given complete, accurate information on ZIKV and the risk for CZVS, including what is not known. Do not make up things you do not know or give false reassurances.
- Recognize the stress on pregnant woman of uncertainty about the diagnosis; provide psychosocial support and links to resources in the community.
- Do not blame or judge women for becoming pregnant or not using an insect repellent.
- Allow women to make decisions on the basis of their beliefs, values, priorities and circumstances, and provide support without judgement.
- Communicate all information clearly, in neutral language; the information should be based on the best available evidence.
- Give women the opportunity to choose from all the available options in accordance with national law, including contraception, discontinuation of pregnancy and carrying a potentially affected pregnancy to term.
- Women's right to choose includes the right to refuse tests and interventions, except for those that are legally required.
- Women's decisions about who to involve in reproductive health decision-making should be respected, and social support should be provided regardless of the decision.

Tips for communicating with caregivers and families after a diagnosis of CZVS

- Start the visit by asking the caregiver or family member what they know about ZIKV. This will provide both a basis on which to build your discussion and insight into how ZIKV and the associated complications are viewed in the community in which you practice.
- Provide accurate, appropriate information for caregivers and families in their own language.
- Reassure the caregiver and family that the child's disability is not their fault, nor is it related to evil spirits or any other myths that may be perpetuated about disability and ZIKV in general. Mothers are particularly vulnerable and often feel guilt and fear. Continued reassurance is an important means of positive support.
- Remember to use positive terminology that promotes the respect and dignity of the child. Acknowledge that the child is not defined by his or her medical conditions alone (e.g. a child with cerebral palsy is not a "spastic child"; a child with intellectual impairment is not "mentally challenged" or "retarded").
- When explaining the diagnosis, focus on positive aspects, without offering false hope.
- Emphasize the opportunities for the growth and development of any child and the importance of stimulating and interacting with the child.
- Convey the uncertainty of the outcomes of an exposed child and the importance of close follow-up regardless of the initial presentation, in view of the various symptoms that may present throughout early infancy and childhood, even in a child who is apparently healthy at birth.

- Communications includes being a role model. Use the child's name, talk and play with the child regardless of his or her level of impairment. Children with disability are at higher risk of decreased interaction, and these interactions are important for both development and inclusion of the child in the family and community.
- The primary caregiver must have support; therefore, encourage partners and family members to attend visits whenever possible.
- Set realistic short-term goals: caregivers and families who hope that a child with disability will be "cured" after therapy will be disappointed, and they are likely to discontinue treatment.
- Emphasize what the child can do and accomplish, rather than his or her disabilities.
- Highlight and encourage any efforts made by caregivers and families.
- Explain that many families with children affected by disability have loving, happy relationships.
- Respect and respond to the concerns of the caregiver and the family.
- Recognize that caregivers and families are often best placed to detect changes in the child's behaviour.
- Remind caregivers and families that regular medical care is essential, although there is no cure for CZVS.
- Children with CZVS are at risk for a broad range of neurodevelopmental complications, including impaired development, seizures, spasticity and visual and hearing impairment. Therefore, close follow-up is needed, even for apparently normal infants, to ensure early identification and treatment of complications.
- Children with CZVS are also more vulnerable to respiratory infections because of the associated dysphagia and spasticity; therefore, when they are ill, they should be seen sooner than the average child.
- Malnutrition is a concern, particularly poor, fragile bones, and nutritional support with monitoring of growth is essential.
- Be prepared to answer difficult questions honestly; describe realistic outcomes, while maintaining hope and acknowledging the uncertainty of the child's prognosis. (See **Box 1**.)
- Recognize that children who have additional health care needs and disabilities may be at risk for neglect and abuse. Provide support for the caregiver and family but also be aware of local reporting laws and child protection services.
- Caregivers and families should know they are not alone. Link them with support groups and other resources in the community, when possible.
- Recognize that caregivers and families affected by CZVS face many challenges in addition to the health of the child, including financial and social concerns. Provide tailored advice and referrals to the available resources in your community.

BOX 1. ANSWERING DIFFICULT QUESTIONS

The most common question is whether there is a cure for CZVS. The answer should be honest (e.g. “There is no cure.”) but also positive (e.g. “You can optimize your child’s ability to grow and develop with therapy and medical support.”).

Many caregivers ask for a prognosis of their child’s functional abilities as he or she grows. This is difficult to do. While a child’s development at certain points has some predictive value, it is limited, as every case is different, and long-term outcomes cannot be predicted. Questions may include whether the child will ever talk, walk, feed him- or herself, go to school or live independently. Restrict your responses to the child’s clinical prognosis, acknowledging the uncertainty.

Broad optimism is also not appropriate because, if the child has severe disability, caregivers and families should be prepared to find everyday tasks difficult. It is important to emphasize that all children, whatever their disability, should attend school when possible.

Sometimes caregivers and families simply ask whether their child will be “normal”. Try not to use the word “normal” but instead focus on the growth and development of the child. Children with neurodevelopmental disabilities may not be the same as their peers, but they can grow and develop at their own rate. It is important to emphasize this to caregivers and families.

KEY MESSAGES

- ➔ *Provide sources of accurate, appropriate information for caregivers and families in their own language.*
- ➔ *Recognize the significant psychosocial stress and stigma associated with ZIKV and with children with disabilities. Clear, non-judgemental communication in a private space is important for care.*
- ➔ *Women should be given all available diagnostic and clinical information on ZIKV, including the options for management of pregnancy, according to local law.*
- ➔ *Focus on the positive aspects whenever possible, without giving false hope, when discussing plans for treatment and the prognosis of a child with CZVS.*



Antenatal guidance for pregnant women in Zika virus-affected areas

Care for the child starts at preconception and continues throughout antenatal care. It is important to recognize that not all exposed pregnant women will have a child with CZVS. While the evidence suggests a significant risk to an unborn child exposed to ZIKV at any stage of pregnancy, a study in Brazil showed that 46% of symptomatic pregnant women who were ZIKV-positive had adverse outcomes (8); however, the exact risk is unknown. Counselling on reducing risk and on reproductive health choices is essential for all women of reproductive age exposed to ZIKV.


LEARNING OBJECTIVES

- ➔ *Identify key aspects of antenatal guidance for women in ZIKV-affected areas.*

Reducing the risk for transmission (9)

- ZIKV can be transmitted sexually. Therefore, couples or women planning a pregnancy and returning from areas where there is known ZIKV transmission should wait for at least 6 months before trying to conceive.
- Pregnant woman and their sexual partners living in areas with active ZIKV transmission should be advised to practice safer sex or to abstain from sexual activity for at least the duration of the pregnancy.
- Pregnant women in areas with active ZIKV transmission should also practice general measures to prevent exposure to ZIKV, including use of insect repellent, protective clothing and mosquito nets.

Antenatal care and testing for ZIKV (9)

- All pregnant women should receive routine antenatal care, including mental health and psychosocial support. (See Module 3.)  At each visit, the woman should have:
 - a clinical assessment for ZIKV,
 - counselling on individual protection against ZIKV and
 - a reminder to report any signs or symptoms of ZIKV immediately.
- All pregnant women with a clinical history suggesting ZIKV during pregnancy should be tested for infection.
- If the first antenatal visit is before 18 weeks, an ultrasound scan should be conducted, if available, for assessment of fetal morphology and gestational age. If fetal brain or other abnormalities are detected and/or a test for maternal ZIKV is positive or inconclusive, a detailed ultrasound evaluation is recommended. After 15 weeks' gestational age, consider amniocentesis, with full disclosure of the risks and the limitations of testing.
- Other known causes of fetal brain or other abnormalities should be ruled out, including other congenital infections (e.g. syphilis, toxoplasmosis, cytomegalovirus, rubella, herpes, HIV); exposure to toxic drugs, chemicals and radiation; genetic abnormalities, e.g. Down syndrome; fetal malnutrition and placental insufficiency.



Assessment and management of congenital Zika virus syndrome

CZVS is a constellation of neurodevelopmental signs and symptoms associated with congenital ZIKV that may manifest prenatally or at any time in infancy. It may include intrauterine growth restriction, microcephaly (which may be congenital or progressive), hydrocephalus, craniofacial disproportion, neuro-imaging abnormalities, irritability, cerebral palsy or spasticity, seizures, arthrogryposis, hip dysplasia, dysphagia, sensorineural hearing impairment and visual impairment, as well as associated developmental impairment.

Comprehensive, long-term management involves local early childhood stimulation programmes, rehabilitation programmes and mental health and psychosocial support. As the course of CZVS is unknown, this section covers screening and evaluation at birth and management in early life. As affected children develop, preparation for school, education programmes and adaptation should be considered, although they are not covered here.

Clinical evaluation and diagnostic testing of newborns

All infants born in areas of ZIKV transmission or to mothers with suspected, probable or confirmed ZIKV should undergo a comprehensive assessment, including measurement of head circumference, assessment for neurological abnormalities and appropriate diagnostic testing (10) (Fig. 1). The assessment should include a review of other potential causes of microcephaly and other congenital anomalies, such as a history of alcohol abuse, a family history of genetic disorders and environmental exposure.

Gestational age is important for determining neurodevelopmental evaluation. It can be assessed on a validated scale or by examining certain features (11), including skin appearance, lens vascularization, breast tissue, ear cartilage, external genitalia and plantar surface.

Head circumference indicates brain growth. The most accurate measurement is taken from the most prominent aspect of the forehead to the widest part of the back of the head, with repeated measurements to ensure accuracy (Box 2).

BOX 2. MEASURING HEAD CIRCUMFERENCE (12)

1. Anchor tape over eyebrows.
2. Pass tape over fullest part at the back of the head.
3. Check correct positioning.
4. Pull tight.
5. Record head circumference (cm) to last completed 1 mm.

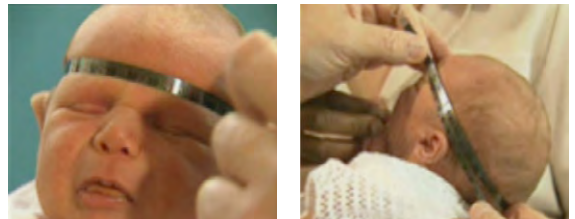


FIG 1. INITIAL EVALUATION OF A NEWBORN POTENTIALLY EXPOSED TO ZIKV



All neonates meeting either of the following:

1. Born to mothers residing in areas of Zika transmission
2. Evidence of Zika infection during pregnancy (either clinical or laboratory) and/or fetal imaging concerning for congenital Zika infection*

Head circ. <-3SD
(Severe microcephaly)



» Perform laboratory testing for ZIKV (RT-PCR in blood or urine; IgM in blood)‡
 » Perform neuroimaging (CT/MRI)
 » Perform TORCH screening



Positive RT-PCR or IgM in blood or urine (or CSF if available)‡

CONFIRMED/PROBABLE CONGENITAL ZIKA VIRUS SYNDROME



Neuroimaging suggestive of Zika infection (without laboratory confirmation)

SUSPECTED CONGENITAL ZIKA VIRUS SYNDROME



Negative ZIKV lab and/or neuroimaging not consistent with ZIKV

NEGATIVE FOR ZIKV DIAGNOSIS

(consider at risk as evidence of infection may appear later)

» **Congenital Zika Virus Syndrome Case Protocol[§]**
 (Neurodevelopmental evaluations recommended at 2-4 weeks, 3m, 6m, 9m, 12m, 18m, 24m with appropriate screening and interventions)

INITIAL ASSESSMENT (WITHIN 24-48H OF BIRTH)[†]

History & exam specifically including head circumference measurement and assessing for risk of maternal ZIKV exposure (by history of exposure to Zika virus, rash during pregnancy, or positive ZIKV lab during pregnancy)



-2SD > Head circ. ≥ -3SD
(Microcephaly)



-2SD ≥ Head circ. ≤ 2SD
(Normocephaly)



Head circ. >2SD
(Macrocephaly)



Are there any of the following concerns noted on evaluation?

- Head appears disproportionately small relative to the face or body
- Infant has abnormal tone (e.g. too stiff or too floppy)
- Seizures
- Vision exam abnormal
- Failed hearing screening
- Difficulty feeding
- Arthrogryposis (e.g. contractures of limbs)
- Abnormal neuroimaging concerning for ZIKV
- Signs of hydrocephalus (e.g. head circumference ≥2SD, excessively sleepy, bulging fontanel, etc)

OR Is the mother confirmed ZIKV positive by lab?



» Continue to monitor routinely – signs/symptoms may appear in later infancy

Close developmental monitoring recommended at minimum visits at 2-4 weeks, 3m, 6m, 9-12m, and 24m. Vision and hearing screens should be performed routinely, including a follow-up physiologic hearing test at least once before age 2y. If any deceleration of head growth or appearance of neurodevelopmental abnormalities without identified etiology, re-investigation for ZIKV is recommended, including complete neurodevelopmental assessment and consideration of neuroimaging and laboratory testing.

**If +TORCH, FAS, or genetic disease suspected, individualized counseling and treatment should be performed*

*As per WHO Interim Guidance: Pregnancy Management in the context of Zika virus infection (2016)

[†]General newborn assessment with basic neurological exam, including standard vision and hearing assessments should be performed on all neonates in Zika affected regions. WHO Child Growth Standards for size at birth should be used to interpret measurements of head size. If accurate gestational age is known, INTERGROWTH-21 Size at Birth Standards are preferred. For preterm neonates, INTERGROWTH-21 Size at Birth Standards for gestational age and sex should be used to interpret measurements

[‡]WHO recommends RT-PCR testing in blood or urine and/or IgM in blood. CSF can be tested but is not necessary for diagnosis. Testing should be done in parallel testing for Dengue and Chikungunya

[§]Detailed guidance for monitoring and evaluation, including neurodevelopmental monitoring, developmental interventions, hearing and vision screening, and psychosocial support are provided in Tables 1 & 2

In order to obtain the most accurate comparison with either WHO child growth standards (12) or INTERGROWTH-21 standards (13), head circumference should be measured within the first 24 h of birth (10). For newborns born at term (37–42 weeks), WHO growth standards at birth should be used to interpret measurements. If the gestational age is known accurately, the INTERGROWTH-21 standards for size at birth are preferred. For preterm newborns, INTERGROWTH-21 standards for size at birth for gestational age and sex should be used to interpret the measurements.

- Assess the *anterior fontanelle* in both the upright and the supine position. A sunken fontanelle is a marker of dehydration, while a tense, bulging fontanelle indicates increased intracranial pressure.
- Assess every newborn for *degree of alertness*. A newborn should have cycles of sleeping and waking (with spontaneous eye opening and arousal from sleep with gentle stimulation), vigorous crying during wakefulness, and consoling appropriately with cares, including feeding and swaddling.

The absence of such expected responses might be a sign of encephalopathy and warrants further evaluation, including for metabolic abnormalities and subclinical seizures.

- Evaluate for *dysmorphic features*. Infants with CZVS have a prominent occiput, extra skin folds (*cutis gyrata*) and craniofacial disproportion (**Fig. 2a**). Dysmorphic features may also provide clues to other disorders, which may present with abnormal brain development and/or microcephaly (e.g. trisomy 21, fetal alcohol syndrome).

- Initial visual assessment: CZVS is associated with both structural and retinal abnormalities (e.g. chorioretinitis, cataract, lens subluxation, coloboma, glaucoma, micro-ophthalmia) (14). Perform a structured eye examination on all newborns.
 - Assess pupillary response by illuminating each eye individually. Look for equal constriction of the pupil in the illuminated eye and consensual response in the opposite eye. Lack of response may indicate an abnormality of the brain, such as increased intracranial pressure (which should also be seen in the appearance of the fontanelle).
 - Visual responses depend on gestational age. An infant should blink to light by 26 weeks, close the eyes to a light stimulus by 32 weeks and track a red ball by 34 weeks. A full-term infant should respond by blinking to light and tracking a red object.
 - Ensure that the infant can move the eyes in all directions.
 - Assess for a red reflex with an ophthalmoscope, by shining a light into the newborn's eyes from a distance of approximately 50 cm. A red light should be seen over each pupil. Dark spots or a white light (e.g. white reflex) are abnormal and may suggest a structural abnormality.
 - When possible, perform a fundoscopic examination. The appearance of necrotic lesions with black or yellow streaks or spots can indicate the presence of chorioretinitis (**Fig. 2b**).
- A *hearing assessment* is an essential component of the evaluation of newborn, as those with CZVS may have sensorineural hearing loss (15).
 - Any infant over 28 weeks' gestation should respond to loud sounds with a startle response or by blinking.
 - When possible, perform a physiological hearing test (AABR or OAE). AABR is preferred as it indicates a broader range of hearing impairments.

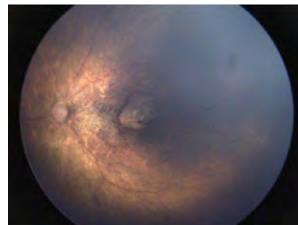
FIG 2. INITIAL EVALUATION OF A NEWBORN POTENTIALLY EXPOSED TO ZIKV

a. Dysmorphic features in CZVS: Note the severe microcephaly and cutis gyrata in the infant shown in the top and right-hand images, and craniofacial disproportion without microcephaly in the image on the bottom.



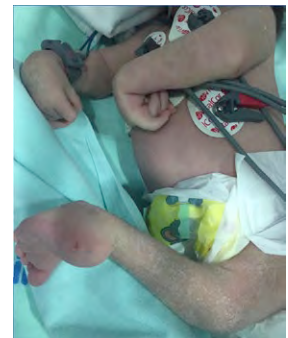
a.

b. Ophthalmological abnormalities in CZVS: Note the optic nerve with increased disc cupping, discrete vascular attenuation and chorioretinal scar with pigmented mottling in the macular region.



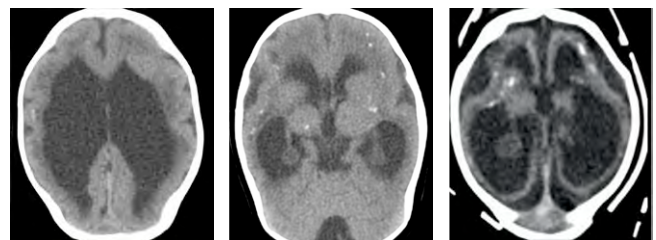
b.

c. Arthrogryposis in CZVS



c.

d. Neuroradiology features of CZVS (computed tomograph scans are for different infants)



d.

Images courtesy of Dr Vanessa van der Linden (a, c, d) and Dr Camila Ventura (b), Recife, Brazil

- Assess for *facial asymmetry* by observing infant at rest and when crying.
- Assess the activity of *cranial nerves* 5, 7, 9, 10 and 12 by watching the infant suck and swallow.
- Assess *muscle tone* by both observation and manipulation. It is best to examine the infant when he or she is slightly drowsy, as tone varies by state.

- The resting position in the first 48 hours of infants of 32 weeks' gestational age and older is limbs flexed close to the body with fisting, after which they have a slightly more relaxed posture. Flexor tone should always be higher in the legs than in the arms; having the legs extended at rest with the arms flexed may be a sign of increased tone (hypertonia).
- Assess for increased (hypertonia) or decreased (hypotonia) tone by gently manoeuvring the extremities. Too much or too little resistance may indicate abnormal tone. Gentle lengthening of the extremities should be possible even in a newborn in the resting position, without too much resistance. The infant should also intermittently open his or her hands; persistent fisting may be a sign of abnormally high tone. Abnormally high tone is rare in newborns and is thus a clinically important diagnostic sign of CZVS when present. Tone should be assessed with the head in the midline so that asymmetries can be detected; asymmetry in tone is always a concern. Be aware that assessment of tone may be limited by joint contractures (arthrogryposis), which is often a consequence of too little movement of the baby in utero and can be a reflection of too high or too low of tone.
- Deep tendon (or muscle stretch) reflexes should be checked at the knees and biceps. It is best, particularly if abnormal tone is present, to use a reflex hammer. The infant should be in an awake state, with the head in the midline. It is important to look for symmetry and briskness. Most reflexes in the newborn are brisk, but persistent clo-

nus (more than five beats) or markedly brisk reflexes should be evaluated further. Plantar responses in the newborn are of limited diagnostic use.

- Asymmetry in either reflexes or plantar response is always a concern and should be evaluated further.
- Checking for normal newborn reflexes in the infant can also help assess healthy neurodevelopment (**Box 3**).

BOX 3. NEWBORN REFLEXES

- **Rooting reflex:** present at birth and disappears by 4 months. The infant turns the head and opens the mouth to follow the direction of mouth stimulation, to find the breast and breastfeed.
- **Sucking reflex:** begins at about week 32 of pregnancy and is fully developed by week 36. Preterm infants may have weak or immature sucking ability.
- **Palmar grasp reflex:** present at birth, disappears at 2–3 months. When the palm is stimulated, the infant closes the fingers to grasp what is in the palm.
- **Moro or startle reflex:** present at birth, disappears at 4–5 months. The infant throws back the head, extends the arms and legs, cries and then pulls the arms and legs back, usually in response to a loud sound or a movement.
- **Stepping reflex:** present at birth, disappears at 2 months. When the infant is placed in an upright position with the back of the foot placed gently on a flat surface, he or she appears to take steps by lifting the foot and placing it back down.

- Check for contractures and arthrogryposis, which have been associated with CZVS (16). It is important to provide early physical therapy and assistive devices for optimal outcomes (Fig. 2c). Contractures are deformities caused by abnormal tone that results in tightening or shortening of the muscle or tendon, restricting movement. Arthrogryposis is congenital joint contractures in two or more areas of the body.
- Observe the infant's movements: spontaneous, fluid movements of the extremities should be seen. Jerky, rhythmic, non-suppressible, and/or stereotyped movements might indicate seizures (See Fig. 3).

Diagnostic tests

- An infant with any of the following should be tested for ZIKV infection and for other congenital infections [syphilis, toxoplasmosis, other (e.g. varicella zoster, parvovirus B19), rubella, cytomegalovirus, herpes simplex virus: TORCH], if not done during pregnancy:
 - severe microcephaly (<-3 standard deviation),
 - evidence of maternal ZIKV infection or
 - abnormal results in a neurological examination or by neuroimaging.
- An infant with suspected CZVS should be examined by brain computed tomography or magnetic resonance imaging for further indications of the diagnosis and prognosis (10).
- Neuroimaging findings that are characteristic of CZVS include subcortical calcification, brainstem or cerebellar hypoplasia, posterior fossa abnormalities, cortical malformations, migrational abnormalities, enlarged ventricles and skull deformities (17) (Fig. 2d).
 - Cranial ultrasound may be considered for general screening when feasible.
 - There is no clear evidence that repeated imaging after diagnosis is warranted, unless clinically indicated.

Neurodevelopmental monitoring and management in early life

Children born in ZIKV-affected areas should be monitored closely during the first years of life, as symptoms may emerge after the newborn period. Children with a diagnosis of CZVS should receive individualized care and support for the associated complications immediately. Children who were at risk for exposure but did not show features of CZVS as a newborn should be monitored closely, and general developmental stimulation should be provided in the community. They should be monitored and evaluated as frequently as necessary, with the recommended minimal frequency shown in Table 1.

Evaluation and management of nutrition and feeding

Poor weight gain and nutrition are of great concern in infants with CZVS. They result from little activity, poor nutritional intake due to limited feeding, an abnormal metabolic demand due to spasticity and common problems of dysphagia or difficulty in swallowing (in 15–60% by the third month of life), gastro-oesophageal reflux and delayed gastric emptying (18).

- All infants born to mothers with suspected, probable or confirmed ZIKV infection or who reside in or have travelled to areas of ongoing ZIKV transmission should be fed according to normal infant feeding guidelines. Exclusive breastfeeding is recommended for the first 6 months of life (19).
- Weight and general growth parameters should be monitored closely at each visit (20), with counselling about a proper diet and nutrition.

- Monitor for dysphagia (difficulty in eating and drinking), as it can result in poor weight gain as well as respiratory complications (20) (**Box 4**). Management of dysphagia includes postural correction, thickened feeds, pacing and spoon placement techniques (20). If possible, this should be done under the guidance of a nutrition, speech or swallowing specialist. Continued feeding difficulty will require guidance for placement of a nasogastric or orogastric tube, when available.
- Guidance should be provided to avoid gastro-oesophageal reflux, including slow feeding, keeping the infant upright immediately after meals and elevating the head of the bed with a support under the mattress.
- Excessive drooling is common in many children with neurodevelopmental impairment and is associated with stigma and an increased risk for respiratory infection (20). Pharmacological therapy can be helpful, although it is often not feasible. Behavioural techniques may be beneficial (**Box 5**).
- Constipation is a common source of discomfort, which can arise from intake of thickened feeds. Routine care should include ensuring that the infant is having normal bowel movements and providing supportive care as needed.
- If weight gain is poor, caloric supplementation can be given when appropriate, through additional feeds, complementary foods rich in vitamins and nutrients and general nutritional counselling.
- Feeds might have to be fortified with micronutrients to overcome poor nutritional status; iron and additional supplementation appropriate for the age and risk factors of the infant should be given according to WHO guidelines (22–24).
- Bone health is a particular concern, given the risk for fractures of this vulnerable population, and appropriate vitamin D and calcium intake should be ensured. Caregivers should be counselled on careful handling of children in order to prevent fractures.

BOX 4. CLINICAL SIGNS OF DYSPHAGIA (21)

- gags, coughs, chokes or vomits when eating or drinking;
- clears the throat often during or after meals;
- has to swallow several times to clear each mouthful of food or drink;
- wheezes during or after eating or drinking;
- has apparent stridor when breathing during eating or drinking;
- becomes breathless, respire more or has laboured breathing during eating or drinking;
- has apparent congestion in the chest or nose after eating or drinking;
- appears to become blue or dusky after eating or drinking;
- generally refuses to eat or drink foods or fluids with certain textures;
- salivates excessively or drools while eating

BOX 5. BEHAVIOURAL TECHNIQUES TO REDUCE EXCESSIVE DROOLING

- Use gentle prompts to guide the infant in swallowing and closing the mouth (e.g. lightly touch the top lip or under the chin).
- Try lip sealing and oromotor exercises (e.g. practice blowing, facial expressions, repeating the syllables “mmm”, “bbb” and “ppp”).
- Where available, oral evaluations with good, routine dental care are important.
- Infants who drool excessively should be referred for speech therapy, when available.

Spasticity and neuromotor evaluation and management

CZVS often results in cerebral palsy, due to brain malformations and injury from exposure to the virus. The spasticity associated with CZVS is often difficult to manage and contributes to neuromotor impairment. Spasticity is a specific type of increased tone (hypertonia) in which there is resistance of muscles to stretching.

- Treatment of abnormalities of tone is essential to maximize active functioning and optimize care, in addition to preventing pain and contractures. Physical therapy, stretching and orthotics can optimize and maintain the range of movement and are essential components of care.
- Physical therapy should be offered to all children with abnormal tone, with early initiation and frequent sessions. In many instances, caregivers and family members can be trained to deliver routine physical therapy to the child several times a week, which is optimal.
- Referral for occupational therapy and assessment of speech and swallowing are recommended, when available, to improve positioning, feeding and communication.
- Positioning is important in managing a child with abnormal tone in order to maximize his or her comfort, ability to play and participation in activities and to prevent complications (e.g. scoliosis, contractures, pressure sores). Caregivers and family members should be given guidance and demonstrations of good positions for children with spasticity. Examples include lying prone or on the side, with support, and objects of interest within easy reach to encourage play and visual coordination.
- Management of spasticity with oral medications can be effective as short-term therapy but should not replace physiotherapy. Diazepam or baclofen (Table 2) can be beneficial, although direct evidence for their use in pain management associated with spasticity or muscle spasms is limited. Use should therefore be based on availability, feasibility and the needs of each child (25,26).

TABLE 2. ORAL MEDICATIONS FOR MANAGEMENT OF SPASTICITY IN CHILDREN WITH CEREBRAL PALSY

Medication	Evidence	Dosing	Side-effects
Oral Diazepam	Effective for short-term treatment. Unclear whether it improves motor function.	<ul style="list-style-type: none"> • Infant aged 1–12 months: start at 0.25mg/kg twice daily • Child 1–5 years: initially 2.5 mg twice daily • Child 5–12 years: initially 5 mg twice daily • Child 12–18 years: initially 10 mg twice daily; maximum total daily dose, 40 mg 	<ul style="list-style-type: none"> • Dose-dependent; include increased salivation, sedation, ataxia and weakness. • Long-term use increases risk for physical dependence. • Abrupt discontinuation increases risk for seizures.
Oral Baclofen	Inconclusive but widely used clinically. Less sedating than diazepam.	<ul style="list-style-type: none"> • Start at the lowest dose (0.3 mg/kg per day 3–4 times daily, increasing gradually each week to 0.75–2 mg/kg daily 3–4 times daily; the lowest effective dose should be given. • Maximum dose should be <40 mg/day for children <8 years and 60 mg/day for those aged 8–18 years. • Review treatment if no benefit after 6 weeks on maximal dose. 	<ul style="list-style-type: none"> • Risks for systemic toxicity, drowsiness and sedation. • Medication should be discontinued slowly due to risks for seizures, hyperthermia, confusion and increased spasticity with abrupt withdrawal.

If available and with appropriate specialist expertise, botulism neurotoxin serotype A injections could be considered for localized/segmental spasticity as a potentially effective therapy (20).

- Children with CZVS who have abnormal tone should have appropriate screening for hip dysplasia (dislocation) by pelvic imaging and, when appropriate, referral for orthopaedic management. 🧑🏻 Screening for clinical signs (e.g. asymmetrical skin folds, hip click) is not sufficient (25, 28):
- Contractures due to abnormal tone are a common problem in children with CZVS; many affected children have arthrogryposis (16). Orthotic braces and devices made or adapted to assist a child in performing specific tasks should be used when available to optimize motor development.
- Children with neuromotor impairment can benefit from a wide variety of assistive devices, and these should be provided, depending on local resources (29). Common types of device are: mobility devices (e.g. walking sticks, wheelchairs), prostheses (e.g. artificial legs), orthoses (e.g. hand splints), visual devices (e.g. glasses, white canes) and hearing devices (hearing aids).
 - Important aspects for their effective use include education, repair, replacement and environmental adaptations in the home and community.
 - For the developing child, these devices will have to be adapted as he or she grows and for specific developmental needs.

Evaluation and management of irritability

- Irritability, which is seen in over 85% of infants with CZVS (18), can be one of the most difficult issues for caregivers and families.
- The irritability associated with CZVS typically resolves within the first few months of life. Nevertheless, they should be evaluated for all possible medical causes and contributing factors. The potential causes include: pain (e.g. contractures, fractures, dental disease), spasticity, gastro-oesophageal reflux, seizures, constipation, acute illness (e.g. infections, abdominal or renal disease), medication effects, poor sleep, non-accidental injury and changes in the home environment.
- If irritability recurs in an older infant, he or she should be evaluated for hydrocephalus and signs of increased intracranial pressure.

Management after excluding treatable medical conditions (30, 31):

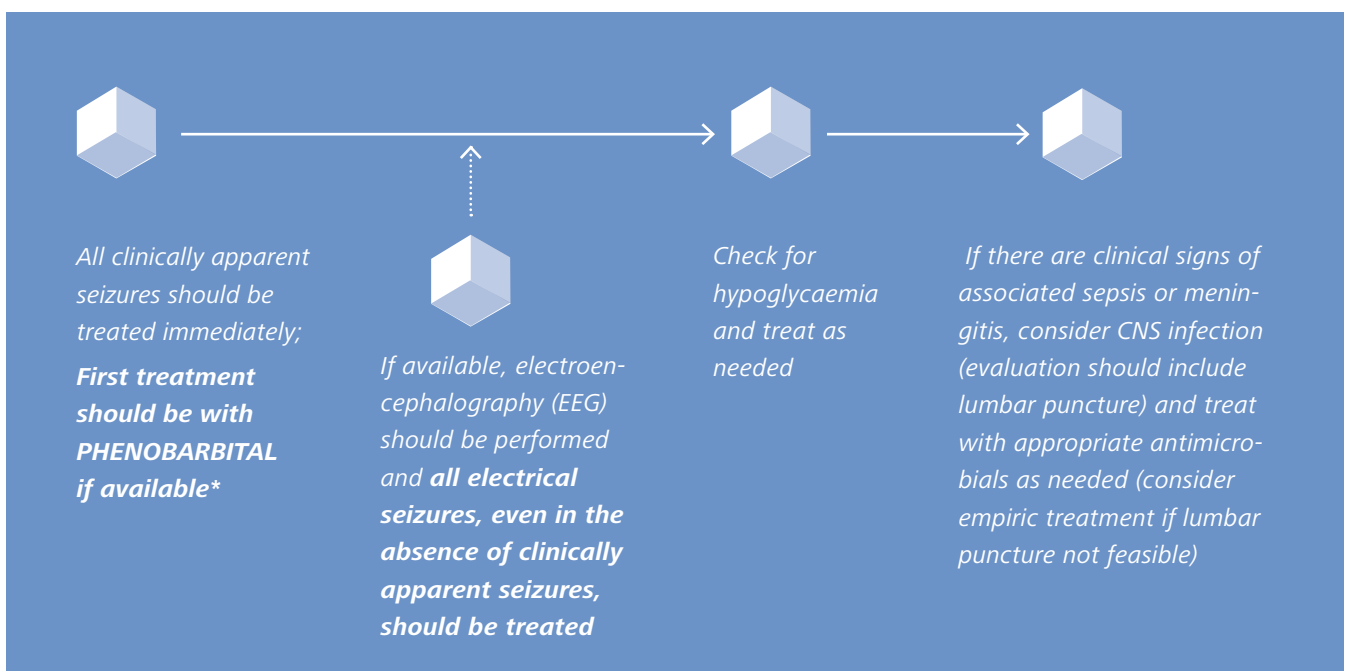
- Discuss sleep, feeding and crying patterns.
- Maximize support for the caregiver, and reassure parents that the excess irritability is not their fault or a sign of bad parenting. Irritability in CZVS is not behavioural, and extra attention and soothing will not harm the child.
- Discuss normal patterns of fussiness and crying.
- Avoid excessive stimulation (lights, sound) when the child is crying or being put to sleep.
- Review settling techniques, e.g. develop routines, particularly for sleep; use techniques such as quiet play, cuddling, settling for sleep in the crib or cot while still awake, holding the infant close and using swaddling; rocking and patting; playing gentle music.
- Remind caregivers and families to respond before the child becomes too worked up.
- Certain medications, such as carbamazepine and gabapentin, can help older infants and children with neuropathic pain, although evidence for their efficacy is limited (32).

- Recognize that excessive irritability can stress the entire household. This is a risk factor for the mental health of caregivers, families and the affected child. Invite caregivers and families to discuss their difficulties, and ensure that the mother has rest and support, as lack of support can result in post-partum depression as well as difficulty in soothing the infant, placing the child at risk for poor adaptive responses, including neglect and abuse (33).

Evaluation and management of seizures and epilepsy

- As CZVS is associated with brain malformations, affected children are at high risk for seizures and epilepsy. Nearly all infants with CZVS have an abnormal EEG, and over 50% have seizures in early infancy (18,30).
- The seizures described in CZVS include infantile spasms and focal seizures. While current reports on epilepsy in CZVS suggest that the seizures are difficult to control, early identification and appropriate treatment remain essential for optimal neurodevelopment. Seizures can take many forms in the developing child. Episodes of decreased responsiveness or abnormal, stereotyped and rhythmic movements should prompt evaluation. Loss of developmental skills should raise concern about “silent” or non-convulsive seizures, which require treatment.
- Seizures may first present at any age, from the neonatal period to later childhood. Children with CZVS should be evaluated throughout childhood, given their risk for epilepsy. Neonatal seizures are treated differently from seizures later in infancy and childhood (Fig. 3).

FIG. 3. MANAGEMENT OF SEIZURES IN NEWBORNS WITH CZVS



Source: reference 31

*Phenobarbital should be used as first-line treatment of neonatal seizures; however, neonates who continue to have seizures despite administration of the maximal tolerated dose of phenobarbital should be given benzodiazepine, phenytoin or lidocaine as a second-line agent (use of phenytoin or lidocaine requires cardiac monitoring facilities).

Seizures in older infants and children

Active seizing in a child should be treated as status epilepticus (32) (**Fig. 4**).

- Neuroimaging (ultrasound in young infants, computed tomography or magnetic resonance imaging in older children) should be considered for children with altered consciousness or a new focal neurological deficit (33).
- A child who appears to be severely ill (e.g. fever with altered consciousness or seizure) should be evaluated appropriately for central nervous system infections, regardless of a diagnosis of CZVS (33).
- Consider a lumbar puncture if a child < 18 months (especially if < 6 months) has complex febrile seizures (e.g. prolonged, focal or recurrent during the same febrile illness), has received antimicrobials before assessment, has not been vaccinated against *Haemophilus influenzae* type B or *Streptococcus pneumoniae* or his or her vaccination status is unknown.
- Delay lumbar puncture until complications have been managed. If the child is unresponsive (e.g. meets the criteria for coma on the WHO Emergency triage, assessment and treatment scale (5): (A) alert, (V) responds to a voice, (P) responds to pain, (U) unresponsive) or has focal neurological signs; signs of brainstem herniation, increased intracranial pressure or respiratory compromise; signs of shock; infection in the skin overlying the site of the proposed lumbar puncture; or evidence of a bleeding disorder.

The risk of a child with CZVS for recurrence of seizures is high; therefore, one unprovoked seizure warrants diagnosis and treatment for epilepsy. If a child with CZVS has recurrent seizures with fever that have no other identifiable cause, he or she should be considered to be at high risk for epilepsy, and a decision to give prophylactic antiepileptic therapy should be made in consultation with the family. In general, while simple or complex febrile seizures in children under 6 years do not warrant prophylactic anticonvulsive treatment, a child with CZVS has abnormal brain development, and consideration of treatment is warranted.

Recognition of the type of seizure is important for proper treatment. CZVS is most commonly associated with infantile spasms and focal seizures. Infantile spasms usually begin in the first year of life (commonly at 3–6 months). They are considered a neurodevelopmental emergency and require specialized treatment (34,35). Spasms are sudden, generally bilateral, symmetrical (although asymmetry is seen) flexor (less commonly, extensor) contractions, which typically occur in clusters (5–100 spasms). They often occur when the infant wakes and may be associated with a cry, although they can occur in any state. Infantile spasms are associated with neurodevelopmental regression, and the outcomes depend on the cause, the time to treatment and the efficacy of treatment. Early diagnosis and rapid treatment are essential. A characteristic EEG pattern known as hypsarrhythmia, notable for a background pattern of high amplitude and disorganized activity, is typically associated. Specialized treatment is warranted for this syndrome (**Box 6**).

Focal seizures are also common in children with CZVS. Antiepileptic drugs should be chosen on the basis of their availability and side-effects and the type of seizure (focal or generalized). Carbamazepine is a good initial option for focal seizures, but phenobarbital, sodium valproate, phenytoin and other locally available medications can be considered (**Table 3**).

The general principles for treating epilepsy (32) are:


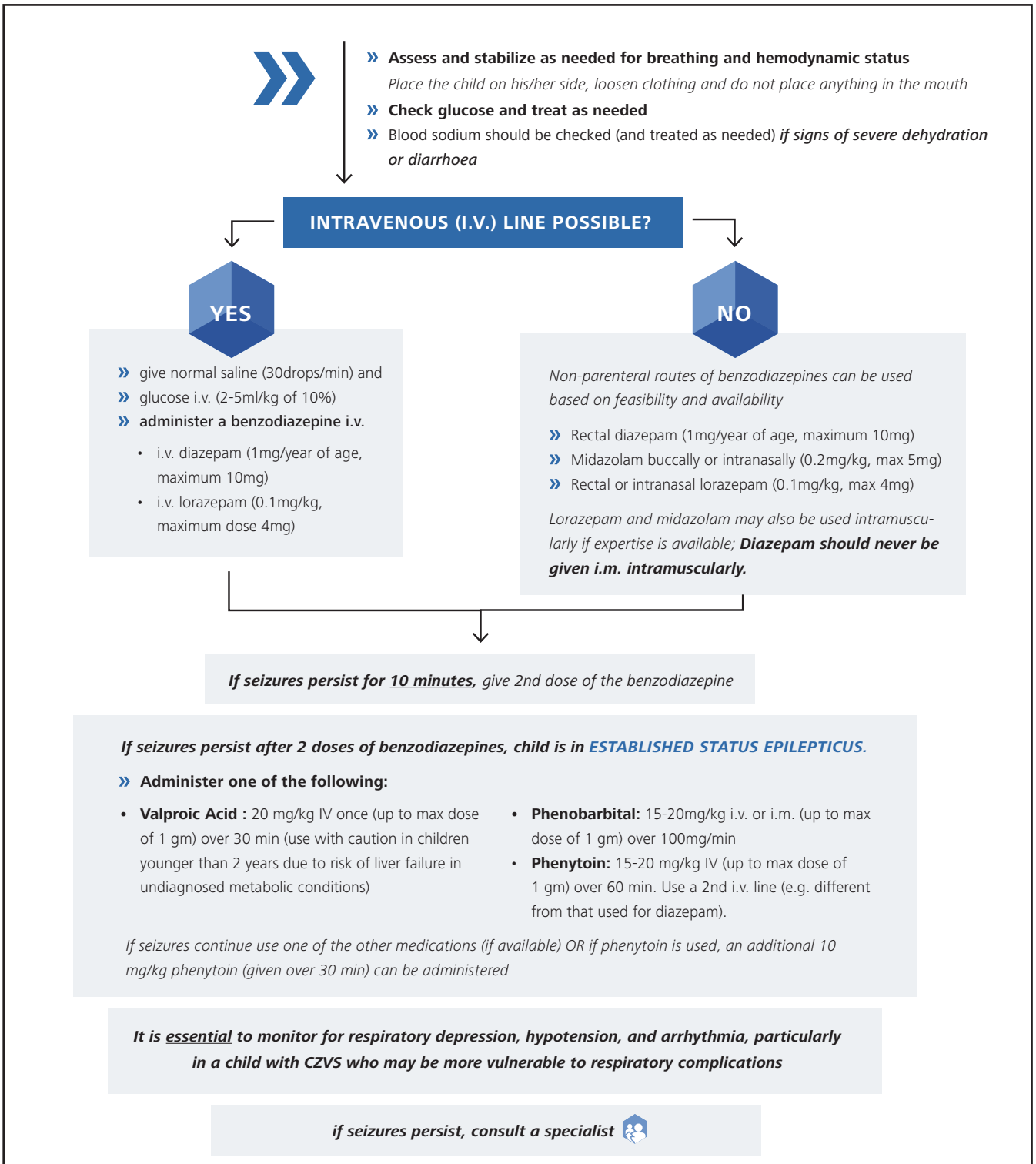
- Choose an antiepileptic drug that will be consistently available.
- Start with only one antiepileptic drug at the lowest dose, and increase the dose slowly until the convulsions are controlled. Add or change to a second drug only if the maximum dose has been reached or adverse effects are noted.
- If feasible, routinely monitor blood count, blood chemistry and liver enzymes.
- Check for drug–drug interactions, as antiepileptic drugs may interact, increasing blood levels, and with other medications. For children living with HIV, sodium valproate is the preferred drug, and referral to a specialist is recommended. 
- All antiepileptic drugs should be discontinued slowly. Stopping them abruptly can result in seizure breakthrough.

FIG 4. MANAGEMENT OF STATUS EPILEPTICUS IN AN OLDER INFANT OR CHILD



BOX 6. MANAGEMENT OF INFANTILE SPASMS (37–41)

Consult, and when possible refer to, a specialist for management guidance.

If available, perform EEGs with the infant awake and asleep before treatment; however, treatment should not be delayed.

Hormonal treatment (including intramuscular adrenocorticotrophic hormone, tetracosactide or high-dose prednisolone) is recommended as first-line treatment, although there is limited evidence that any of these options is superior to the others. Low-dose prednisolone is not recommended, as it has little efficacy. Close monitoring of hormonal treatment is necessary; when possible, therapy should be initiated in a hospital.


Possible side-effects of hormonal therapy include: elevated blood pressure, weakened immune system, irritability, gastric irritation and ulcers, hyperglycaemia and increased appetite; appropriate counseling and monitoring of these side-effects are important.

When possible, before treatment is started, the child should be screened for tuberculosis, have a complete blood count and urine glucose measurement, and weight and blood pressure should be checked. Blood pressure, weight and, when possible, urine glucose should be monitored routinely during treatment.

Although hormonal treatment is the recommended first-line treatment, vigabatrin may be considered if available.

A follow-up EEG is recommended after 2 weeks of treatment to assess its efficacy.

A child with epilepsy should be assessed every 3 months to determine (32) whether the frequency of seizures has been reduced by more than a 50%.

- If the child is not improving, review adherence to medications and side-effects or difficulties that may be compromising administration.
- If the child is taking the medication properly, consider increasing the dose to the maximal dose, if there are no adverse effects.
- If the response is still poor, consider changing the medication. The new medication should be given at the optimal dose while the first medication is slowly discontinued. It is best to use only one medication, if possible.
- Consider referral to a specialist. 

Seizures in children with CZVS may be difficult to control fully. The treatment goals should be discussed with the caregivers and families at every visit, and a balance should be struck between the best seizure control that can be achieved and minimal side-effects from the medication (e.g. excessive sedation).

Children should be free of seizures for 2 years before discontinuation of the medication can be considered. Because of the risks associated with CZVS, many children may require life-long treatment. The risk that seizures will recur if the medication is discontinued should be discussed fully with the family before discontinuation is attempted.

TABLE 3. ANTIEPILEPTIC THERAPY

Drug	Dose	Side-effects	Contraindications and cautions
Carbamazepine	<ul style="list-style-type: none"> • Start at 5 mg/kg daily in 2–3 divided doses. Increase by 5 mg/kg daily each week. • Maximum: 40 mg/kg daily or 1400 mg daily. 	<ul style="list-style-type: none"> • Common: Sedation, confusion, dizziness, ataxia, double vision, nausea, diarrhoea, benign leukopenia. • Serious: Hepatotoxicity, cardiac conduction delay, low sodium. 	<ul style="list-style-type: none"> • Caution in people with history of blood disorders, kidney, liver or cardiac disease. • Dose might have to be adjusted after 2 weeks due to induction of its own metabolism.
Phenytoin	<ul style="list-style-type: none"> • Start at 3–4 mg/kg daily in 2 divided doses. Increase by 5 mg/kg daily every 3–4 weeks. • Maximum: 300 mg/day 	<ul style="list-style-type: none"> • Common: Sedation, confusion, dizziness, tremor, motor twitching, ataxia, double vision, nystagmus, slurred speech, nausea, vomiting, constipation. • Serious: Haematological abnormalities, hepatitis, polyneuropathy, gum hypertrophy, acne, lymphadenopathy. 	<ul style="list-style-type: none"> • Lower doses for peoples with kidney or liver disease.
Phenobarbital	<ul style="list-style-type: none"> • Start at 2–3 mg/kg daily in 2 divided doses. Increase weekly by 1–2 mg/kg daily, depending on tolerance. • Maximum: 6 mg/day. 	<ul style="list-style-type: none"> • Common: Sedation, hyperactivity in children, ataxia, nystagmus, sexual dysfunction, depression. • Serious: Liver failure (hypersensitivity reaction), decreased bone mineral density. 	<ul style="list-style-type: none"> • Contraindicated in people with acute intermittent porphyria. • Lower doses for people with kidney or liver disease. • Caution for use in children with behavioural disorders.
Sodium valproate	<ul style="list-style-type: none"> • Start at 15–20 mg/kg daily in 2–3 divided doses. Increase each week by 15 mg/kg daily. • Maximum: 15–40 mg/kg daily. 	<ul style="list-style-type: none"> • Common: Sedation, headache, tremor, ataxia, nausea, vomiting, diarrhoea, weight gain, transient hair loss. • Serious: Impaired hepatic function, thrombocytopenia, leukopenia, drowsiness or confusion (valproate-induced hyperammonemic encephalopathy, a sign of toxicity), liver failure, haemorrhagic pancreatitis. 	<ul style="list-style-type: none"> • Caution if underlying or suspected hepatic disease. • Caution in children < 2 years of age, in whom metabolic diseases may not yet be apparent. • Drug–drug interactions: levels decreased by carbamazepine, increased by aspirin.

Source: reference 32

Education on epilepsy and seizures should be provided at each visit (32). Describe what a seizure is (e.g. excess electrical activity), in order to correct inaccurate beliefs and the stigma surrounding seizures and epilepsy. Reassure caregivers and families that there are effective options for treating epilepsy, and tell them that compliance with medication and adherence to developmental support programmes are important for optimizing the child's neurodevelopmental outcome.

Provide instructions on managing seizures at home:

- Lay the child on his or her side, with the head turned to ease breathing (**Fig. 5**).
- Do not put anything into the mouth or restrain the child.
- Make sure the child is breathing.
- Bring or call the nearest health provider if you are concerned about the child's breathing, the seizure is lasting longer than 5 min, or the child does not wake up after the seizure.

FIG 5. SEIZURE RESCUE POSITION



Developmental monitoring and support

Children develop progressively, from mastering simple skills to learning more complex skills. The environment, interactions with the family and the child's play all play important roles in their development.

Children with CZVS are at risk for delayed development. The delay is difficult to predict, as each child is unique and the range of abilities acquired depends on many factors, including the extent of injury from the virus and the associated complications.

- Optimizing the environment with interactions and stimulation by the caregiver and community development programmes are essential.
- The development of all children with or at risk for CZVS should be monitored routinely with a local or an adapted global screening tool. General achievement milestones can be used to assess delays, continued progress, stagnation or regression of development (**Table 4**) in all domains: sensory–motor, cognitive, communication and social–emotional.
- The development of premature infants should be monitored on the basis of their corrected gestational age until they reach 2 years of age.
- Failure to meet developmental milestones in any domain should prompt referral for evaluation by a development specialist and coordination of care.  Early motor development (e.g. rolling within the first 3 months, hand preference before 1 year) and other signs of abnormal tone (e.g. walking on the toes) should also prompt evaluation.
- Children with developmental disorders may have difficulty in facing new situations; caregivers and families should be advised to ensure regular times for eating, playing, learning and sleeping and to involve the child in everyday life as much as possible.
- Methods of adaptive communication could be incorporated into developmental support programmes, when appropriate. Caregivers and families should be encouraged to speak to the child and narrate their activities aloud, as this helps the child gain understanding of language, even if it is nonverbal. Advise caregivers and families to teach the child gestures and hand signals to communicate simple things, like “Yes” or “No”. Communication skills, both nonverbal and verbal, should be a focus of therapy, with the goals tailored to the extent of the child's disabilities.
- Developmental support programmes are coordinated with caregivers, families and community resources. Recommendations for play and stimulation therapy should be provided, regardless of resource availability. Local resources or global tools such as the UNICEF Early child development toolkit (31) or the WHO Care for child development (42) could be used.
- As the child develops, promote inclusive attitudes in the community, including maintaining attendance in school and participation in social activities.


TABLE 4. DEVELOPMENTAL MILESTONES AND WARNING SIGNS

Age	Needs of the child (in addition to responsive parenting)	Expected development	Warning signs (refer for further evaluation)
Birth – 3 months	<ul style="list-style-type: none"> • Protection from physical danger • Adequate nutrition • Adequate health care, such as vaccination, oral rehydration therapy and hygiene • Appropriate language stimulation • Motor and sensory stimulation 	<ul style="list-style-type: none"> • Begin to smile, track people and objects with their eyes • Prefer faces and bright colours • Turn towards sound • Discover feet and hands 	<ul style="list-style-type: none"> • Poor suckling at the breast • Stiffness or little movement of arms and legs • Seems excessively floppy • Asymmetrical movement • Little or no reaction to loud sounds or bright lights • Excessive irritability
4–6 months	<ul style="list-style-type: none"> • Protection from physical danger • Adequate nutrition • Adequate health care, such as vaccination, oral rehydration therapy and hygiene • Appropriate language stimulation • Motor and sensory stimulation 	<ul style="list-style-type: none"> • Smile • Develop preferences, generally for parents and older siblings • Repeat actions with interesting results • Listen intently • Respond when spoken to • Laugh and gurgle • Imitate sounds • Explore hands and feet • Put objects in mouth • Sit when propped • Roll over • Grasp objects without using the thumb 	<ul style="list-style-type: none"> • Does not smile at caregiver by 4 months • Stiffness or difficulty in moving limbs • Asymmetrical movement • Little or no response to sounds, familiar faces or the breast • Abnormal eye movement and/or eye alignment • Does not turn to sound
7–12 months	<ul style="list-style-type: none"> • Protection from physical danger • Adequate nutrition • Adequate health care, such as vaccination, oral rehydration therapy and hygiene • Appropriate language stimulation • Motor and sensory stimulation 	<ul style="list-style-type: none"> • Remember simple events • Identify themselves, body parts and familiar voices • Understand their name and common words • Say first meaningful words • Explore objects and find hidden objects • Put objects in containers • Sit alone • Pull themselves up to stand and walk 	<ul style="list-style-type: none"> • Stiffness or difficulty in moving limbs • Asymmetrical movement • Does not sit without support by 10 months • No response to caregiver • Does not make sounds in response to others • Does not look at moving objects • Abnormal eye movement and/or eye alignment • Does not make gestures, such as waving
1–2 years	<p>In addition to requirements for healthy growth in infancy, provide support in acquiring:</p> <ul style="list-style-type: none"> • motor, language and thinking skills • independence • self-control • opportunities to play with other children <p>Health care should include de-worming</p>	<ul style="list-style-type: none"> • Imitate adult actions • Speak and understand words and ideas • Experiment with objects • Walk steadily, climb stairs and run • Recognize ownership of objects • Develop friendships • Solve problems • Show pride in accomplishments • Begin make-believe play 	<ul style="list-style-type: none"> • No response to others • Cannot walk without assistance by 14 months • Cannot walk independently by 18 months • Asymmetrical walking • Does not respond to name by 12 months • Has no single words • Does not make gestures, such as pointing • Caregiver concerns about vision • Abnormal eye movement and/or eye alignment
2–3.5 years	<p>In addition to requirements for healthy growth in infancy, provide opportunities to:</p> <ul style="list-style-type: none"> • make choices • engage in dramatic play • listen to increasingly complex books • sing favourite songs • solve simple puzzles 	<ul style="list-style-type: none"> • Enjoy learning new skills • Learn language rapidly • Gain increased control of hands and fingers • Act more independently 	<ul style="list-style-type: none"> • No interest in playing • Falls frequently • Difficulty in manipulating small objects • Cannot understand simple messages • Inability to speak using several words • Does not make gestures such as waving or pointing • Caregiver is concerned about vision • Abnormal eye movement and/or eye alignment

Vision in children with CZVS

Current estimates show that up to 55% of children with CZVS have visual impairment (14). Functional assessments should be conducted to identify visual impairments and treatment incorporated into developmental support programmes.

- Functional assessments of vision should be performed as per the management protocol (Table 1) and in assessing general developmental milestones (Table 4).
 - Ask caregivers and family members to assess whether the child's vision appears normal for his or her age (44).
 - Newborns should blink when a light is flashed into their eyes.
 - By 2–3 months, infants should look at a face 10–20 cm away.
 - By 3 months, an infant should fix and follow a dangling object.
 - By 4 months, an infant should watch an adult 1.5 m away.
 - By 5 months, an infant should blink in response to a threat (e.g. silent, sudden movement close to the face).

- An external examination should be performed to assess structural abnormalities.
 - Assess pupillary response to identify any irregularity or asymmetry of the pupils.
 - Assess ocular alignment (e.g. for strabismus): have the child focus on a light reflected in the centre of each pupil.
 - Assess for abnormal eye movements, e.g. nystagmus.
 - If available, refer for ophthalmological evaluation  (ideally by the age of 3 months).

Visual impairment in CZVS can present in many ways. Management depends on the problems of the child and local resources.

Hearing in children with CZVS

Children with CZVS are at risk for mild-to-profound sensorineural hearing impairment, with an estimated prevalence of 6% (15).

A behavioural evaluation of hearing should be performed at each visit, as per the management protocol (Table 1) and in assessing general developmental milestones (Table 4). This includes general blinking or movement to a sound by a newborn, turning to sound in early infancy and progressing to mimicking sounds throughout infancy to language acquisition in the second to third year of life.

- A physiological hearing screen (OAE or AABR) should be performed at least twice by the age of 2 years, the first before 3 months of age (10). Screening should be repeated if there is concern about a hearing impairment in the behavioural evaluation. When available, AABR testing is recommended for high-risk infants or as secondary screening after OAE, as it captures a broader range of hearing loss (both cochlear and retrocochlear). OAE can be used for general screening.

- Early developmental support for children with hearing impairment is essential for language development and communication, with adaptation over time.

- An identified hearing impairment should be followed by an evaluation for a hearing aid, if available. Hearing interventions should be incorporated into the child's developmental support programme in order to tailor communication therapy to the child's ability and needs.

Routine care and support of a child with CZVS

● **Newborn care and support** (45)

- Skin-to-skin contact is recommended for the first hour of life for all newborns; if the child weighs < 2 g, Kangaroo Mother Care should be initiated.
- Start breastfeeding within the first hour, as soon as the infant shows readiness to feed, and allow breastfeeding on demand.
- Give intramuscular vitamin K (phytomethadione) to all newborns (1 ampoule of 1 mg/0.5 mL or 1 mg/mL) once. (Do not use a 10 mg/mL ampoule.) For preterm newborns, give 0.4 mg/kg (maximum dose, 1 mg).
- Keep the umbilical cord clean and dry.
- Apply antiseptic eye drops or ointment (e.g. tetracycline) to both eyes once, according to national guidelines.
- Give oral polio, hepatitis B and bacille Calmette-Guérin (BCG) vaccines, depending on national guidelines.

● **Routine paediatric care, including vaccinations, is the right of all children, including those with disability, who are often most at risk** (46), and should be provided to children with CZVS.

- Children with CZVS are more vulnerable to infections, particularly respiratory infections. All acute illnesses should be treated promptly according to the WHO guidelines for integrated management of childhood illnesses and particularly in this population, which is at higher risk for morbidity and mortality.
- General protection against mosquitoes is recommended. Specifically, infants and children should sleep under insecticide-treated bednets, which should be dipped into insecticide every 6 months (47).
- Be attentive to any signs of sexual or physical abuse and neglect at each visit, as children with a disability may be at higher risk for abuse. Any suspected abuse or neglect must be evaluated, if possible in an interview or an examination in a private space. If abuse or neglect is suspected, engage local child protection service and community resources, support the family, and ensure close follow-up.

KEY MESSAGES

- ➔ *All infants born in ZIKV transmission areas or to mothers with suspected, probable or confirmed ZIKV infection should have a comprehensive neurological assessment, with head circumference measurement and vision and hearing testing, within 24-48 hours.*
- ➔ *Children with confirmed or probable CZVS should then be followed with visits at the ages of 2 weeks, 3 months, 6 months, 9 months, 12 months, 18 months and 24 months at a minimum. Children with potential exposure but no confirmed diagnosis should continue to be monitored closely for development and growth at local or community health clinics.*
- ➔ *Breastfeeding is recommended for all infants, regardless of ZIKV infection, for a minimum of 6 months.*
- ➔ *Many children with CZVS have difficulty in feeding. Growth, including weight gain and overall nutritional status, should be monitored closely as part of routine care, and nutritional support should be provided.*
- ➔ *Children with CZVS commonly have significant spasticity that requires physical therapy, stretching and orthotics.*
- ➔ *Caregivers and families should be instructed in positioning children with spasticity to minimize discomfort and optimize development.*
- ➔ *Children with CZVS are at high risk for seizures, most commonly infantile spasms and focal seizures.*
- ➔ *Appropriate, timely management of acute seizures and chronic epilepsy management can improve neurodevelopmental outcomes.*
- ➔ *Children born in ZIKV-affected areas or to mothers with suspected, probable or confirmed ZIKV infection should be closely monitored and supported during their development, including vision and hearing screening.*
- ➔ *Routine newborn, infant and child health care should be provided for children with CZVS, including scheduled vaccinations and management of acute illnesses.*

LINKS TO RELEVANT RESOURCES

General information about ZIKV:

<http://www.who.int/emergencies/zika-virus/en/>; <http://www.who.int/mediacentre/factsheets/zika/en/>

Questions about ZIKV: <https://www.cdc.gov/zika/about/questions.html>

ZIKV Communication materials:

http://www.paho.org/hq/index.php?option=com_content&view=article&id=11554&Itemid=41715&lang=en

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of ZIKV infection: <http://www.who.int/csr/resources/publications/zika/psychosocial-support/en/>

ZIKV ethics consultation: Ethics guidance on key issues raised by the outbreak:

http://iris.paho.org/xmlui/bitstream/handle/123456789/28425/PAHOKBR16002_eng.pdf

WHO recommendations on antenatal care for a positive pregnancy experience:

<http://apps.who.int/iris/bitstream/10665/250796/1/9789241549912-eng.pdf>

Pregnancy management in the context of Zika virus infection: Interim guidance update:

http://apps.who.int/iris/bitstream/10665/204520/1/WHO_ZIKV_MOC_16.2_eng.pdf

WHO. Rapid advice guidelines: <http://www.who.int/csr/resources/publications/zika/assessment-infants/en/>

Sites for paediatric neurological examination videos (local resources recommended for use where available):

http://library.med.utah.edu/pedineurologicexam/html/newborn_n.html; <http://mrcpch.paediatrics.co.uk/neurology/neurology-videos/>

WHO. Guidance on feeding and nutrition:

http://www.who.int/nutrition/publications/guidelines/infantfeeding_zikavirus_transmission/en/

Daily iron supplementation in infants and children:

http://www.who.int/nutrition/publications/micronutrients/guidelines/daily_iron_supp_childrens/en/

Infant and young child feeding: http://www.who.int/maternal_child_adolescent/documents/9789241597494/en/

WHO nutrition guidelines:

<http://www.who.int/nutrition/publications/micronutrients/guidelines/mmpowders-infant6to23mons-children2to12yrs/en/>

Essential nutrition actions: Improving maternal, newborn, infant and young child health and nutrition

http://www.who.int/nutrition/publications/infantfeeding/essential_nutrition_actions/en/

Guidelines on Community-based Rehabilitation (CBR): <http://www.who.int/disabilities/publications/cbr/en/>

WHO. Neonatal seizures guidelines: http://www.who.int/mental_health/publications/guidelines_neonatal_seizures/en/

mhGAP v2.0: Epilepsy module: http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/

WHO. Paediatric emergency triage, assessment and treatment:

http://www.who.int/maternal_child_adolescent/documents/paediatric-emergency-triage-update/en/

Developmental management and references for monitoring tools (local resources are recommended when available):

<http://siteresources.worldbank.org/EXTAFRREGTOPEDUCATION/Resources/444707-1291071725351/ExaminingECDtoolkit-FULL.pdf>; <https://www.unicef.org/dprk/e.cd.pdf>

Early child development kit: https://www.unicef.org/videoaudio/PDFs/Activity_Guide_EnglishFINAL.pdf

WHO. General guidance for newborn and child care: http://www.who.int/maternal_child_adolescent/documents/en

Guidelines on maternal, newborn, child and adolescent health:

http://www.who.int/maternal_child_adolescent/documents/guidelines-recommendations-newborn-health.pdf

Integrated Management of Childhood Illness Chart booklet:

http://www.who.int/maternal_child_adolescent/documents/IMCI_chartbooklet/en/

Essential newborn care course: http://www.who.int/maternal_child_adolescent/documents/newborncare_course/

MODULE 2

Assessment and management of people with Guillain Barré syndrome and other neurological complications triggered by Zika virus

This module provides practical guidance on assessing and managing people with Guillain Barré syndrome and other neurological conditions associated with Zika virus.

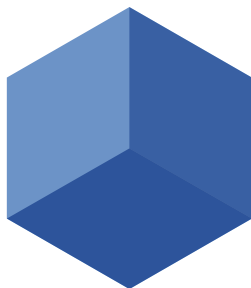
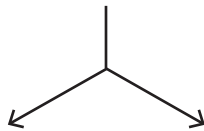
- 2.1 *Introduction*
- 2.2 *Supportive communication*
- 2.3 *Assessment of people with Guillain Barré syndrome in the context of Zika virus*
- 2.4 *Management of Guillain Barré syndrome triggered by Zika virus*



Person exposed to ZIKV with weakness in legs



Neurological assessment in health care facility, confirming ZIKV and excluding other diagnoses



Provide immunotherapy (health care facility)



Supportive care and management of acute complications (health care facility)



Rehabilitation (transition to community or home)



Introduction

ZIKV in children and adults typically runs a mild course; however, acute, potentially life-threatening neurological complications may occur. One such complication is GBS, an acute medical condition in which the body's immune system attacks the nerves that control motor function and sensation (48, 49).

LEARNING OBJECTIVES

- ➔ *Understand the definition, risk factors and possible triggers of GBS.*
- ➔ *Identify the spectrum of neurological complications triggered by ZIKV.*

Basic facts about GBS triggered by ZIKV

GBS is an acute, potentially life-threatening medical condition usually triggered by an infection, in which the body's immune system attacks nerves that control motor function and sensation (48,49). Other triggers of GBS include infection by *Campylobacter jejuni*, HIV, dengue virus and chikungunya virus (48, 49); however, GBS in middle-aged adults is most frequently triggered by ZIKV (50–54).

The most common presenting symptom of GBS is progressive bilateral ascending limb weakness. Other symptoms include

weakness of the facial muscles, difficulty in moving the eyes, difficulty in swallowing or speaking and or tingling or numbness in the arms or legs (48,49). GBS can affect the nerves that control respiration, heart rate and blood pressure. Up to 25% of people with GBS develop complications that require intensive care, including mechanical ventilation, and over 50% have some degree of autonomic instability (i.e. abnormal heart rhythm and fluctuations in blood pressure). Overall, they have a 5% risk for death despite the best of care (55,56).

Other neurological conditions associated with ZIKV are described in **Box 7**.

BOX 7. OTHER NEUROLOGICAL CONDITIONS ASSOCIATED WITH ZIKV

Other neurological conditions have been identified in people with ZIKV, although more rarely than GBS. Studies are under way to evaluate the spectrum of associated neurological conditions (57–67).

- **Myelitis** is a condition that causes inflammation of the spinal cord, in which people have rapid onset of weakness and sensory alterations including numbness and weakness, often associated with bowel, bladder or sexual dysfunction (68).
- **Meningitis and encephalitis** are conditions involving inflammation of the protective coverings of the meninges (meningitis) and the brain (encephalitis), in which people have acute fever, headache, neck stiffness and confusion (69).
- **Acute disseminated encephalomyelitis** is a condition involving inflammation of the brain and spinal cord, in which people present with a variety of neurological symptoms, including confusion, headache, weakness and sensory abnormalities such as numbness and tingling (70).
- **Sensory neuropathy** is a condition in which people have numbness, tingling and/or burning pain in their distal limbs (71).
- **Myasthenia gravis** is an autoimmune neuromuscular condition characterized by muscle weakness that increases during periods of activity and improves after periods of rest. It can result in double vision, drooping eyelids and difficulty in speaking and walking. The muscles that control breathing may also be affected (72).
- **Hearing and visual symptoms** (73,74)
- **Memory loss and cognitive impairment** (75).



Supportive Communication

General principles of communication (76, 77)

- Establish a rapport, listen to the person, demonstrate empathy, facilitate care and support, and supply information.
- Develop mutual respect and a common understanding of the care plan. Establish routine plans for communication throughout the person's hospital stay.
- Provide evidence for management of the medical condition, using simple language and avoiding medical jargon. Develop a nurturing, secure decision-making environment.
- Understand the person's perspective of their condition, including their ideas, beliefs, concerns, expectations and feelings. Be sensitive to cultural differences and perceptions.

Communicating with an adult affected by GBS triggered by ZIKV (78)

- Remember that affected people will have a variety of emotions. Use simple language and be calm, even when the person is acutely distressed and communication is difficult. The person affected by GBS should always feel respected, cared for and empowered.
- Provide information about the illness. Listen and encourage questions.
- An affected person should know that the acute phase, however frightening, is temporary. Be realistic, while maintaining hope; remind them that over 80% of people with GBS recover completely.
- Emphasize the need for psychosocial support, recognizing that it may be difficult for previously independent individuals to ask for help and that support systems may not be readily accessible.

Communicating with caregivers and families

- Be aware of your ethical obligations and of local laws with regard to a person's right to privacy and medical decision-making. Caregivers and families are an essential part of care and support but should be included only when the person affected by GBS or the person appointed to make medical decisions is in agreement.
- Encourage caregivers and families to provide positive encouragement throughout hospitalization, reminding them that the patient might experience a variety of emotions during the course of the illness.
- Recognize the needs of caregivers and families, and express empathy for their difficulty in watching a loved one in distress.

KEY MESSAGES

- ➔ *Communication is a critical component of the care and support of people affected by neurological complications associated with ZIKV.*
- ➔ *The health care professional should establish a rapport, listen to affected people and their caregivers and families, demonstrate empathy, facilitate care and support and clarify information.*



Assessment of people with Guillain Barré syndrome in the context of Zika virus

LEARNING OBJECTIVES

- ➔ *Be able to perform an initial clinical assessment of a person with a neurological syndrome that may be associated with ZIKV.*
- ➔ *Understand the diagnostic criteria and triage of people with GBS.*
- ➔ *Understand the laboratory evaluation of a person presenting with an acute neurological syndrome in a ZIKV-affected area.*
- ➔ *Apply the Brighton criteria for GBS in the context of ZIKV.*
- ➔ *Know the indications for lumbar puncture, neurophysiology testing and neuroimaging in a person with neurological symptoms in the context of ZIKV.*

Clinical history

A medical history is a structured assessment conducted to obtain a comprehensive picture of a person’s health problems (79) (Table 5). It includes assessment of:

- current and previous health problems, including any current medications;
- information about the person’s presenting symptoms:
 - location;
 - quality and severity;
 - chronology, duration, frequency, periodicity;
 - when (under what circumstances);
 - aggravating and alleviating factors; and
 - the overall course and effect on normal activities;
- any other symptoms in the body systems under consideration; and
- any history of similar symptoms.

TABLE 5. ESTABLISHMENT OF A CLINICAL HISTORY

Clinical features	Questions
Prodromal illness	<ul style="list-style-type: none"> • Travel history, history of mosquito bites or other exposures, sex history • Have you had any fevers in the last few months? If yes, when were the fevers, and how high was your temperature? • Did you have any associated symptoms including chills, sweats, rashes, eye irritation/redness?
Weakness	<ul style="list-style-type: none"> • What is the location, quality, severity, and duration of symptoms of leg and arm weakness? • Do you have any problems walking?
Sensory	<ul style="list-style-type: none"> • Are you having any tingling, burning sensation or numbness in your arms and/or legs? • Do you have any abnormal (band -like) sensations around your chest or abdomen?
Autonomic features	<ul style="list-style-type: none"> • When was your last bowel movement? • Are you have any difficulty urinating or have you been losing your urine? • Are you having any difficulty feeling when you go to the bathroom? • In male patients, do you have any new problems with having an erection? • Have you had any chest pain and palpitations?
Respiratory symptoms	<ul style="list-style-type: none"> • Do you have any shortness of breath at rest or when you are moving?
Encephalopathy	<ul style="list-style-type: none"> • Are you having any confusion, irritability or psychiatric symptoms? (ask caregivers as well). If yes, what is the nature of these symptoms? • Do you have any headaches? If yes, please describe the location, quality, severity and duration of symptoms?
Bulbar symptoms	<ul style="list-style-type: none"> • Are you having any difficulty speaking or have you noticed any change in quality of speech? • Are you having any difficulty swallowing (have you noticed any recent choking on your food)?

Source: reference 79

Physical examination

- A complete physical examination should be performed, including assessment of lungs, heart, abdomen and extremities.
- Vital signs, including blood pressure and heart rate should be closely monitored, with an electrocardiogram.
- When the equipment is available, patients' heart rate should be monitored continuously, as they may have rapid changes in heart rate and blood pressure.
- Particular attention should be paid to the respiratory status of the patient (see complications below).
- Bowel sounds should be monitored, as their absence may indicate abnormal bowel function, which requires medical treatment.
- The patient's ability to urinate and have bowel movements should also be monitored. The patient should be asked daily about the frequency of bowel movements and his or her ability to urinate. Pain in the lower abdomen may be suggestive of urinary retention.

Neurological examination

A complete neurological assessment should be performed, with attention to:

- **Eye movements:** Assess the full range, up, down, left and right.
- **Facial strength:** Assess symmetry and weakness on smiling and squeezing eyes shut.
- **Speech and ability to swallow:** Evaluate the volume of speech, whether it is slurred or sounds "wet", if the patient has difficulty in swallowing secretions.
- **Motor strength:** Evaluate for weakness of the limbs and symmetry.
- **Muscle tone:** Assess flaccid (or reduced) muscle tone by asking the patient to relax and then passively moving each limb at several joints.
- **Reflexes:** Evaluate the weak limbs for decreased or absent deep tendon reflexes.
- **Sensation:** Evaluate all limbs for decreased or absent sensation to light touch, painful stimuli, temperature or vibration.
- **Gait:** Evaluate the person's ability to ambulate. If the patient is weak, be aware that he or she may be at risk of falling and should be assisted by at least two people. If the patient cannot lift his or her arms and legs off the bed, gait should not be assessed.

A clinical case of GBS should meet all the following criteria (80):

- bilateral and symmetrical weakness of the limbs;
- decreased or absent deep tendon reflexes in the weak limbs;
- flaccid (or reduced) muscle tone;
- monophasic illness (the condition usually does not recur);
- Interval between onset and greatest weakness, 12 h to 28 days' and
- absence of an identified alternative cause of the weakness.

Laboratory evaluation (81,82)

If ZIKV is suspected to have triggered GBS, laboratory testing should be done to identify the virus. Testing for the trigger is not, however, required and should not delay initiation of treatment for GBS.


When people with suspected GBS are tested for ZIKV, they should also be tested for HIV and for any organism relevant to the local epidemiology.

- Laboratory testing for ZIKV as a trigger for GBS should be done according to WHO interim guidance (81).
- Blood for testing for ZIKV and other flaviviruses should be taken before treatment with intravenous immunoglobulin.
- Testing of cerebrospinal fluid (CSF), including reverse transcriptase-polymerase chain reaction and serological testing (e.g. immunoglobulin M, immunoglobulin G, neutralizing antibodies or antibody index) should also be considered (see below).
- If the patient is a child under 15 years of age, stools should be tested locally according to polio surveillance guidelines.

Lumbar puncture (83,-85)

Lumbar puncture (also known as a spinal tap) is a medical procedure in which a needle is inserted into the spinal canal to collect CSF for diagnostic testing.

Indications:

- If GBS is suspected, a lumbar puncture may be done, although sampling of CSF should not delay management. (See section 2.4.)  2.4
- In GBS, CSF is sampled for albuminocytological dissociation (in which the protein concentration is higher than the normal value and the total white blood cell count is < 50 cells/ μ L) (86).
- Sometimes, early in the course of GBS, the results of lumbar puncture may be in the normal range; if there is a strong suspicion of GBS, however, treatment should be initiated. CSF examination may be repeated 1–2 weeks after the onset of symptoms if the diagnosis of GBS remains uncertain.

Contraindications:

- raised intracranial pressure, as indicated by papilloedema on ophthalmological examination;
- a low platelet count or other bleeding problem; or
- suspected infection in the area surrounding the spinal cord.

Complications:

- Lumbar puncture is a relatively safe procedure, although minor and major complications may rarely occur, including headache, infection and bleeding.
- Cerebral herniation can occur in patients with signs of increased intracranial pressure.
- Other temporary, minor neurological symptoms such as pain or numbness in the legs and back pain are more common.

Neurophysiological testing (87,88)

- Neurophysiological testing includes electromyography and nerve conduction studies to record the electrical activity of the peripheral nerves, which can provide useful supporting information when there is clinically suspected GBS. Testing and interpretation of the results require specialized equipment and knowledge. Such studies are not required to make a clinical diagnosis of GBS and should not delay treatment.
- Neuroimaging is not necessary to make a diagnosis of GBS but may be used to identify other neurological complications of ZIKV (Box 8).
- People who meet the clinical case definition of GBS, CSF albuminocytological dissociation and neurophysiological findings consistent with GBS, should be categorized at level 1 of diagnostic certainty according to the Brighton criteria (Table 6) for surveillance and reporting purposes.

BOX 8. NEUROIMAGING FOR OTHER NEUROLOGICAL COMPLICATIONS OF ZIKV

- If myelitis or acute disseminated encephalomyelitis is considered a possible diagnosis, affected people should undergo spinal cord imaging (magnetic resonance with contrast if available).
- If meningoencephalitis or acute disseminated encephalomyelitis is considered a possible diagnosis, affected people should undergo brain imaging (magnetic resonance with contrast if available).
- Neuroimaging should not delay management.

TABLE 6. BRIGHTON CRITERIA FOR THE CASE DEFINITION OF GBS FOR SURVEILLANCE PURPOSES

Level 1 of diagnostic certainty	Level 2 of diagnostic certainty	Level 3 of diagnostic certainty
<ul style="list-style-type: none"> • Bilateral and flaccid weakness of the limbs; AND • Decreased or absent deep tendon reflexes in weak limbs; AND • Monophasic illness pattern, and interval between onset and nadir of weakness between 12h and 28 days. and subsequent clinical plateau; AND • Absence of identified <i>alternative</i> diagnosis for weakness; AND • Cytoalbuminologic dissociation (i.e. elevation of CSF* protein level above laboratory normal value and CSF total white cell count <50 cells/μl; AND • Electrophysiologic findings consistent with GBS. 	<ul style="list-style-type: none"> • Bilateral and flaccid weakness of the limbs; AND • Decreased or absent deep tendon reflexes in weak limbs; AND • Monophasic illness pattern, and interval between onset and nadir of weakness between 12h and 28 days. and subsequent clinical plateau; AND • Absence of identified <i>alternative</i> diagnosis for weakness; AND • CSF total white cell count <50 cells/μl (with or without CSF protein elevation above laboratory normal value): OR electrophysiologic studies consistent with GBS if CSF not collected or results not available. 	<ul style="list-style-type: none"> • Bilateral and flaccid weakness of the limbs; AND • Decreased or absent deep tendon reflexes in weak limbs; AND • Monophasic illness pattern, and interval between onset and nadir of weakness between 12h and 28 days. and subsequent clinical plateau; AND • Absence of identified <i>alternative</i> diagnosis for weakness.

Source: reference 80

*Cerebrospinal fluid (CSF)

KEY MESSAGES

- ➔ *GBS should be suspected in a person with bilateral and symmetrical weakness of the limbs with associated decreased or absent deep tendon reflexes in the limbs.*
- ➔ *Lumbar puncture for sampling of CSF and neurophysiology testing can provide supportive information for a diagnosis of GBS, although they are not required to diagnose GBS and should not delay management.*
- ➔ *Neuroimaging is not required in cases of suspected GBS.*



Management of Guillain Barré syndrome triggered by Zika virus

GBS is a potentially life-threatening illness. Supportive medical care, monitoring and evaluation for whether immunotherapy is required should be performed rapidly and concurrently.

LEARNING OBJECTIVES

- ➔ *Knowledge of the key aspects of clinical management of people presenting with acute GBS.*
- ➔ *Understand indications for immunotherapy in GBS.*
- ➔ *Knowledge of monitoring and supportive and critical care of people presenting with GBS.*
- ➔ *Recognize key components of early inpatient and outpatient rehabilitation care. (See Manual for community workers).*

Immunotherapy in GBS (89–104)

- Immunotherapy should be provided immediately to people with GBS who have rapidly progressive limb weakness and are unable to walk unaided and those who become progressively unable to speak or swallow. The GBS disability score (Table 7) can be used to assess whether immunotherapy is indicated. People with a GBS disability score > 2 should usually receive immunotherapy.
- Intravenous immunoglobulin or plasma exchange are recommended treatments for GBS. These treatments have been shown to be equally efficacious. Treatment should be based on availability. Steroids have not been shown to be effective in GBS.
- People with GBS should be treated as soon as possible.

Monitoring and supportive care

GBS is a potentially life-threatening condition, primarily because of the risk for respiratory compromise due to weak muscles. All people with a clinical diagnosis of GBS should be admitted to hospital and monitored closely.

Any person with rapid progression of motor weakness, signs of respiratory distress, bulbar symptoms (i.e. difficulty in swallowing or speaking) or signs of autonomic dysfunction (marked fluctuations in blood pressure and/or heart rate) should be admitted to a higher level of care (intensive care unit) where continuous cardiac monitoring and ventilator support are available.

Because of potential complications involving several organ systems, GBS is often treated in multidisciplinary care. The health care professionals who provide care and support may include nurses, occupational and physical therapists and physicians (56, 105–115).

TABLE 7. GBS DISABILITY SCORES

Grade	State
1	Normal functional state
2	Able to run with minor signs and symptoms
3	Able to walk 5 m independently
4	Able to walk 5 m with aid
5	Bed- or chair-bound
6	Requires assisted ventilation
7	Death

Source: reference 104

The complications may include:


- worsening neurological status;
- respiratory failure requiring intubation;
- autonomic dysfunction, including marked fluctuations in blood pressure and heart rate and slowing or blocking of digestion, with difficulty in urinating or having bowel movements; and
- systemic infections, particularly pneumonia.

Supportive care should include:

- prophylaxis for deep-vein thrombosis,
- pain monitoring and treatment,
- nutritional support,
- prevention of bed sores,
- bowel and bladder care,
- prevention of corneal ulceration if facial weakness is present,
- early initiation of a multidisciplinary rehabilitation programme and
- mental health and psychosocial support.

Close monitoring of the person's progress through the course of his or her illness is critical.

Monitoring strength

Neurological aspects should be monitored frequently (see 3.3)  3.3 in all people with GBS. Those in the acute phase should be evaluated several times a day, as their medical condition can worsen rapidly. Arm and neck strength should be assessed in particular, as this is an indicator of respiratory strength. As the person's medical condition stabilizes (in the plateau and recovery phases), clinical evaluations may be less frequent but should be at least daily.

Respiratory monitoring

Bedside evaluation should be made of breathing, with measurements including oxygen saturation (by pulse oximetry) and respiratory muscle strength. Hypoxia (low oxygen) appears before CO₂ levels rise in the blood, making pulse oximetry an important tool, if available (111–113).

Clinical markers of failing respiration include:

- rapid, substantial weakness, such as inability to lift the elbows or the head off the bed;
- shallow or rapid breathing;
- difficulty in speaking or inability to count to 15 in one breath;
- paradoxical breathing, i.e. inward movement of abdominal muscles during inspiration; and
- inability to cough.

Pulmonary function testing can be used when available. If it is, vital capacity and maximum inspiratory and expiratory pressure should be assessed. A vital capacity < 20 mL/kg, a maximum inspiratory pressure of < 30 cm H₂O or a maximum expiratory pressure < 40 cm H₂O are signs of impending respiratory failure. A quick decline in vital capacity is also a sign of

worsening respiratory status and potential respiratory failure. In any of those cases, intubation and mechanical ventilation should be provided. Gradual removal from the ventilator should be guided by overall clinical improvement, as shown by more strength on neurological examination and better results in pulmonary function tests.

Autonomic dysfunction (109–114)

Abnormal functioning of the autonomic system can include abnormalities in the heart rate or rhythm, blood pressure, breathing and digestion. Heart rate, heart rhythm and blood pressure should be monitored frequently, ideally continuously, for all people in the acute phase of GBS.

Respiratory monitoring should be instituted at the time of admission and continued until recovery has begun in patients who do not require mechanical ventilation.

The ability to have bowel movements and urinate may also be affected, and supportive treatment, including daily auscultation of bowel sounds, should be provided as necessary.

Supportive care (105)



Prevention of deep venous thrombosis:

- Deep venous thrombosis is formation of a blood clot in a vein in the leg or arm, which can cause swelling, redness and warmth and be life-threatening, as the clot can travel to the lungs.
- People who are mobile should continue to be so during hospitalization and recovery. In people who are not mobile, deep venous thrombosis is best prevented with appropriate medication (e.g. heparin), pneumatic boots if available and/or movement of the legs while in bed (both passive and active).

Metabolism: nutrition, hydration and electrolytes:

- People with GBS, particularly if they are on ventilatory support, often have increased caloric needs.
- Provide hydration as clinically warranted with oral or intravenous fluids.
- A low sodium level is common in GBS and should be monitored and treated.
- As these patients may have difficulty in swallowing, they should be monitored carefully to detect any sign of choking while eating or drinking. A nasogastric tube might have to be placed.
- When available, consultation on nutritional support is recommended.

Pain management (115-117):

- People with GBS should be asked routinely about pain, as pain is frequent in all phases of GBS, and support should be provided.
- Pain due to damaged nerves is frequent in patients in the plateau and recovery phases and may require medication and psychosocial supportive care. (See 3.4 and the Manual for community workers, Module 3.)  [3.4](#)  3
- Use of any sedating medications, such as opiates, should be closely monitored and ideally avoided, given the risk for respiratory failure. If available, gabapentin or carbamazepine may provide some relief of neuropathic pain in the acute phase and tricyclics in the recovery phase.

Skin:

- People with GBS who are paralysed and in bed for a long time are at increased risk for skin ulcers. They may not be aware that their skin is under continued pressure or may not have the strength to reposition themselves.
- Routine prevention should be performed, including inspecting the skin and back.
- If wounds develop, the affected people should be rotated frequently, and attempts should be made to decrease the pressure on the lesions.

Inpatient rehabilitation (118)

Rehabilitation is most effective when delivered early. It should be initiated soon after admission of a person with GBS and provided during all phases of care and support, including in an intensive care unit.

Early therapy helps prevent skin breakdown and other musculoskeletal problems, and key elements of a therapy programme include taking pressure off the areas of the body at risk for pressure ulcers, joint and limb positioning and prevention of weakness.

The rehabilitation team should provide frequent education and training for people with GBS and their caregivers and families. They should also observe caregivers and families while they give bedside assistance.

Fatigue is a common feature of GBS and can intensify with exercise. Rehabilitation should be modified in accordance with the symptoms of fatigue.

Initial evaluation by the rehabilitation team:

- a sensory assessment, by asking patients whether they are sensitive to touch and, if so, where and what types of touch are aggravating or painful;
- inspection of the skin for lesions or pressure spots;
- range of movement of the ankles, knees and hips;
- depending on the findings, assessment of the functional tasks at the person's workplace and/or leisure activities; and
- assessment of functional mobility and observation of a brief gait or with an assistive device, as foot and wrist drop are not uncommon and may require bracing or splinting to prevent contractures.

Interventions during the acute phase of the illness should also include:

- assisting in clearing the airways by teaching breathing exercises and coughing techniques;
- maintaining the range of movement of muscles and joints with gentle passive movements through the full range at least three times of day, especially the hips, shoulders, wrists, ankles and feet; preventing foot drop by motion and stretching exercises to assure the normal range of the ankle joint;
- preventing pressure sores by keeping pressure off bony prominences and re-positioning to support weight distribution, ideally every 2 h from supine to lying; and
- minimizing damage during transfers by providing appropriate positioning and stabilization with pillows, and involving caregivers and families in providing care and support, by educating them in appropriate handling techniques and support during transfers with minimum risk to the person with GBS and the caregivers and family members.



Note that a comfortable position for a person with weakness or paralysis of the legs is lying supine, arms at the sides, elbows slightly flexed, wrists up, fingers gently flexed and the thumb flexed in abduction.

During the plateau phase, rehabilitation should also include:

- respiratory support with activities to optimize lung function;
- strengthening exercises according to the person's degree of weakness, starting with short, frequent periods of exercise;
- assessment for foot or wrist drop and provision of splints as necessary; and
- assistance in self-care.

Be attentive to fatigue during rehabilitation exercises, and slow or reduce them as necessary. A person's rehabilitation should be adapted to his or her capacity in order to maintain encouragement and effort. The rehabilitation team should provide advice for management of fatigue.

Recognize that pain may be a significant issue. Low pressure wrappings can decrease sensitivity to light touch. Reassure and explain to the person that pain is a normal part of the recovery process.

Rehabilitation during the recovery phase is delivered in the community and at home. (See the Manual for community workers, Module 3.)  

KEY MESSAGES

- ➔ *The main components of care are acute management and immunotherapy, management of medical complications with clinical monitoring and supportive and critical care as necessary, and rehabilitation.*
- ➔ *Complications of GBS may include worsening neurological status, respiratory failure requiring intubation and autonomic dysfunction, including marked fluctuations in blood pressure and heart rate.*
- ➔ *A key to a good outcome is diligent daily attention to the person's needs through multidisciplinary care. Supportive care should include:*
 - *prophylaxis for deep-vein thrombosis,*
 - *monitoring and treatment of pain,*
 - *nutritional support,*
 - *prevention of bed sores,*
 - *bowel and bladder care,*
 - *prevention of corneal ulceration if facial weakness is present,*
 - *early initiation of a multidisciplinary rehabilitation programme and*
 - *early initiation of mental health and psychosocial support.*

Rehabilitation is the mainstay of care and support for people with GBS. Initiation of rehabilitation shortly after admission, even to a critical care unit, is essential.

LINKS TO RELEVANT RESOURCES

Institute for Health care Communication: <http://healthcarecom.org/>

WHO fact sheet GBS: <http://www.who.int/mediacentre/factsheets/guillain-barre-syndrome/en/>

Breastfeeding in the context of Zika virus: Interim guidance:

http://apps.who.int/iris/bitstream/10665/204473/1/WHO_ZIKV_MOC_16.5_eng.pdf

Assessment and management of Guillain Barré syndrome in the context of Zika virus: Interim guidance update:

http://apps.who.int/iris/bitstream/10665/204474/1/WHO_ZIKV_MOC_16.4_eng.pdf

The GBS/CIDP Foundation International: <https://www.gbs-cidp.org/>

3

MODULE

Mental health and psychosocial support for people affected by complications associated with Zika virus

This module provides guidance for delivering mental health and psychosocial support to people affected by complications associated with Zika virus.

- 3.1 *Common reactions and assessment of mental health and psychosocial needs*
- 3.2 *Psychosocial interventions*
- 3.3 *Management of severe conditions*
- 3.4 *Specific considerations for people with Guillain Barré syndrome*

3.1

Common reactions and assessment of mental health and psychosocial needs

Pregnant women, caregivers and families in ZIKV-affected areas may have significant psychosocial and mental health concerns. Those affected by complications (including CZVS and GBS) should be given full mental health and psychosocial support. The people affected, their caregivers and families may feel overwhelmed, confused or frightened by the complications associated with ZIKV. Assessments for the common reactions that can affect mental health and wellbeing are an important part of comprehensive care provided by health care professionals.


LEARNING OBJECTIVES

- ➔ *Recognize that pregnant women in ZIKV-affected areas may be fearful and distressed about their pregnancy because of concern about the risk for CZVS.*
- ➔ *Recognize the stressors faced by caregivers and families of children with neurodevelopmental disability and specifically CZVS.*
- ➔ *Identify and design interventions to provide basic psychosocial support and links to social support, and know when referral to a mental health specialist may be required. 🧑🏻‍🦲*
- ➔ *Link caregivers and families to community resources and multidisciplinary care available in their area.*

Common reactions

People may react in various ways to being affected by ZIKV and its potential consequences. It is normal for caregivers and families to experience short-term emotional distress in reacting to an unusual situation. Women who contracted ZIKV infection during pregnancy and/or caregivers and families who are told their child may have CZVS might be more likely to develop symptoms of distress. Health care professionals may see the following reactions from caregivers and families:


- Irritability, anger (not feeling supported for the new challenges of caregiving they will face; anger at the injustice, thinking, “Why me?”);
- guilt, shame (blaming themselves for the condition that the infant has, for feeling helpless or needing support from others);
- insomnia or nightmares;
- physical symptoms (shaking, headaches, feeling very tired, loss of appetite, aches and pains) with no organic cause;
- crying, sadness, depressed mood;
- grief, which is a normal response to any major loss, including the loss of a child or a family member’s health or well-being. Grief has both mental and physical effects. People grieve in different ways and there is no right or wrong way to feel grief;
- excessive worry, anxiety and fear (uncertainty and fear of the unknown and the effect that such complications will have on the family).

These are normal reactions to the challenges that caregivers and families face. If such reactions are observed, an assessment should be conducted with the questions listed in **Box 9**, and section 3.2 should be consulted for psychosocial interventions.  **3.2**

Some of these psychological reactions are also common and normal during pregnancy, such as feeling very tired or having difficulty in sleeping. Women experiencing psychological distress might have physical symptoms, such as exacerbated headaches. The bond or attachment that mothers develop with their infant might also be threatened by complications associated with ZIKV. Mothers might feel detached or resentful toward their child, either during pregnancy or in the early stages of the child’s life.

Most emotional reactions recover spontaneously, although they can progress to severe mental health problems. It is important that health care professionals be able to identify severe problems and support people in managing their mental health needs or in accessing the appropriate specialist services (4).

The partner, father or close family may react similarly to the stress and uncertainty of the situation, to the unknown future of the child and to the effect it will have on the family. The mental health and psychosocial needs of family members should also be assessed. Close family may be an important source of care and support for caregivers after a diagnosis of complications associated with ZIKV. The health professional could contact community workers who might be facilitating peer support groups for caregivers and family members.

A variety of social problems can arise for caregivers and families affected by complications associated with ZIKV, such as difficulties in intimate partner relationships, social isolation and financial strain due to challenges in working (119). Community workers can provide follow-up and home visits that might not be feasible for health care professionals. (See Manual for community workers, Module 2.)  **2**

Be alert for people with more severe presentations. Symptoms are considered severe when people cannot function in their daily lives, such as parents who are unable to get out of bed to care for their children, go to work or do housework. Symptoms are also considered severe if they endanger the person, such as self-harm or suicide, or other people.

BOX 9. ASSESS CURRENT STRESSORS, COPING STRATEGIES AND SOCIAL SUPPORT

Current stressors

- What is your greatest worry these days? What are your most serious problems right now? How severe are these problems?
- How are these problems or worries affecting you?

Coping strategies

- How do you deal with these worries or problems every day?
- What are some of the things that give you comfort, strength and energy?
- What activities do you enjoy?

Social support

- Who do you feel most comfortable with in sharing your problems?
- When you are facing difficulties, who do you turn to for help or advice?
- How is your relationship with your family?

Duration and severity of symptoms

- For how long have you felt sad or worried?
- To what extent are these stressors affecting your daily life, such as relationships with family and friends or your job or studies?

Assessment of mental health and psychosocial needs

By asking supportive, non-judgemental questions, assess current stressors, coping strategies, social support and the duration and severity of symptoms (see Box 9). Explore harmful alcohol or drug use by explaining that the questions are part of the routine assessment and asking them in a non-judgemental, culturally sensitive way, for example:

- “I have to ask you a few routine questions as part of the assessment. Do you drink alcohol? [If yes] How much per day or per week?”
- “Do you take any tablets when you feel stressed, upset or afraid? Is there anything you use when you are in pain? Do you take sleeping tablets? [If yes] How many do you take per day or per week? Since when?”

Depression and other mental disorders should be assessed in caregivers and family members who have not been functioning well for a long time (e.g. > 2 weeks). Health care professionals should monitor caregivers and family members for depression during antenatal and postnatal visits (**Table 8**). They should be alert to common complaints of moderate–severe depressive disorder and ask whether they are experiencing:

- low energy, fatigue or sleep problems;
- multiple persistent physical symptoms with no clear cause (i.e. aches and pains);
- persistent sadness or depressed mood, anxiety; or
- loss of interest in or pleasure from activities.

All illnesses associated with pain, physical disability, neuro-developmental impairment and distress increase the risk of suicide. Health care professionals should include suicide risk assessment as part of their routine clinical practice. Using an open, non-judgemental approach, elicit possible suicidal thoughts and suicide attempts, remembering that asking about self-harm does not provoke acts of self-harm:

- Open broadly. For example, “What are your hopes for the future?”
- If the person expresses hopelessness, ask whether he or she has thoughts of suicide. “Do you feel that life is worth living?”, “When people feel very bad, they sometimes have thoughts of committing suicide. Have you had any thoughts like that?” or “Do you think about hurting yourself?”
- If they do have thoughts of self-harm, ask them whether they have a plan of self-harm or suicide. “Have you made any plans to hurt yourself or end your life?”



If you suspect that someone might be at risk of self-harm or suicide, do not leave them alone, remove all means of self-harm, and refer them to a mental health professional immediately. 

TABLE 8. ASSESSMENT FOR DEPRESSION




Step	Description
<p>Step 1: Determine whether the person has moderate–severe depressive disorder</p>	<p>The person has had at least one of the following core symptoms of depressive disorder for at least 2 weeks:</p> <ul style="list-style-type: none"> • persistent depressed mood, or • markedly diminished interest in or pleasure from activities, including those that were previously enjoyable, which may include reduced sexual desire. <p>The person has had at least several of the following additional symptoms of depressive disorder to a marked degree (or many of the listed symptoms to a lesser degree) for at least 2 weeks:</p> <ul style="list-style-type: none"> • disturbed sleep or sleeping too much, • significant change in appetite or weight (decrease or increase), • beliefs of worthlessness or excessive guilt, • fatigue or loss of energy, • reduced ability to concentrate and sustain attention on tasks, • indecisiveness, • observable agitation or physical restlessness, • talking or moving more slowly than usual, • hopelessness about the future, or • suicidal thoughts or acts. <p>The individual has considerable difficulty in daily functioning in personal, family, social, educational, occupational and other important domains.</p> <p>If any of these are present for at least 2 weeks, moderate–severe depressive disorder is likely.</p> <p>If delusions or hallucinations are present, treatment for depressive disorder must be adapted; refer to a specialist.</p> <p>If the person does not meet all the above criteria, they do not have depression; however, basic psychosocial interventions are essential.</p>
<p>Step 2: Determine other possible explanations for the symptoms (other than moderate-severe depressive disorder)?</p>	<p>Rule out (and treat as appropriate) concurrent physical conditions that may resemble depressive disorder (e.g. anaemia, hypothyroidism).</p> <p>Rule out a history of manic episodes.</p> <ul style="list-style-type: none"> • Rule out normal reactions to major loss (e.g. diagnosis of Zika complications, bereavement, or displacement) where symptoms do not cause significant difficulty in daily living and are short in duration. <p>Rule out prolonged grief disorder: symptoms include severe preoccupation with or intense longing for the deceased person accompanied by intense emotional pain and considerable difficulty in daily functioning for at least six months. Consult a specialist if grief disorder is suspected. </p>
<p>Step 3: Identify other severe symptoms or conditions</p>	<p>Assess the person for thoughts or plans of self-harm or suicide (4).</p> <p>Assess harmful alcohol or drug use (4).</p>

Source: reference 4

3.2

Psychosocial interventions



Psychosocial interventions involve a wide variety of services, resources and approaches for changing behaviour and supporting people who are reacting to stressors. The interventions can be delivered in both health care facilities and the community by general health care professionals.

The interventions described in this section are not stand alone; they can be used in combination with one the care and support described in modules 1 and 2.   

LEARNING OBJECTIVES

- ➔ *Assess and manage mild-to-moderate mental health and psychosocial problems.*
- ➔ *Be able to provide effective psychosocial interventions to people affected by the complications associated with ZIKV.*
- ➔ *Recognize and adapt interventions according to the cultural and spiritual beliefs of the affected person.*
- ➔ *Refer to a mental health specialist for management of more severe conditions.*
- ➔ *Refer to community workers for family and community level psychosocial support, such as peer groups.*



INTERVENTION A:***Supportive communication***

In the delivery of any care, ensure supportive communication in psychosocial support tailored for each individual. (See section 1.1)  

INTERVENTION B:***Identify and respond to immediate needs and concerns (120)***

One of the first interventions that health care professionals should provide is helping people affected by complications associated with ZIKV in addressing their immediate needs and concerns.

Look

- Observe the safety of individuals, caregivers and families.
- Observe people with obvious urgent basic needs, such as food, shelter, health care and hygiene.
- Observe people with serious distress reactions, and assess them according to the questions listed in **Box 9** and **Table 8**.  

Listen

- Try to understand what is most important to them at the moment and their current priorities. For example, “What are some of the concerns you have for your child?”
- Listen to people and help them feel calm. **Refer to Intervention E** for relaxation exercises.

Link

- Help people to address their basic needs and to access services in the community, e.g. housing, education or social welfare services that may be involved in the response to ZIKV.
- Help people cope with their problems **(see intervention D on coping and intervention F on problem-solving)**.
- Give accurate information about the transmission of ZIKV, diagnosis, safety and security to the caregiver, family and child.
- Connect people with loved ones and social support **(see intervention C)**.

INTERVENTION C:***Link to social support (121)***

People tend to cope better when they have friends, family members, or community groups who can offer care and support. If the person has a partner, it is usually helpful to include that person in discussions to encourage support for one another.

- Recognize that emotional distress can affect a person’s ability to get support when they need it.
- Help the person to identify supportive, trusted family members, friends and community members and the ways in which each can provide support.
- Refer to a trained community worker who can facilitate more social support and links to resources in the community or peer support groups.

INTERVENTION D:***Discuss positive coping methods (122)******Discourage negative coping strategies***

- Don’t take drugs, smoke or drink alcohol.
- Don’t sleep all day.
- Don’t work all the time without any rest or relaxation.
- Don’t isolate yourself from friends and loved ones.
- Don’t neglect basic personal hygiene.
- Don’t be violent.

Encourage positive coping strategies

- Get enough rest.
- Eat as regularly as possible, and drink water.
- Talk and spend time with family and friends.
- Discuss problems with someone you trust.
- Do activities that help you to relax (walk, sing, pray).
- Take physical exercise.

INTERVENTION E:***Offer stress reduction and relaxation exercises (121)***

Stress is a common, normal response to difficult situations. Several simple relaxation exercises and techniques can help in reducing the symptoms of stress. Health care professionals can teach caregivers and families techniques such as slow breathing (**Box 10**) and advise the person to practice this exercise at home or at work whenever he or she experiences any of the emotional or physical symptoms of stress.

There may be stress management techniques in the culture in which health care professionals are based that could be used for relaxation. Explore these with caregivers and families.

INTERVENTION F:***Discuss alternative methods for dealing with problems (123)***

An essential part of care by health care professionals is the provision of support in dealing with daily problems, including time management, financial strain, limited services and resources and sleep deprivation.

When daily challenges cannot be solved or reduced, problem-solving techniques may be used to cope emotionally. Discuss possible solutions and coping methods for the problems identified, prioritize them, and discuss how to implement the solutions (**Table 9**). In general, do not give direct advice but encourage people to find their own solutions.

BOX 10. SLOW BREATHING TECHNIQUE

Explain the goal: I am going to teach you how to breathe in a way that will help relax your body and your mind. It will take some practice before you feel the full benefits of this breathing technique.

When we feel stressed, our breathing becomes fast and shallow, making us feel tense. To relax, you must start by changing your breathing.

Relaxing the body (demonstrate for and with the person): Before we start, relax your body. Gently shake and loosen your arms and legs. Let them go floppy and loose. Roll your shoulders back, and gently move your head from side to side.

Slow breathing:

- Now, place one hand on your belly and the other hand on your upper chest. I want you to imagine that you have a balloon in your stomach, and, when you breathe in, you are going to blow the balloon up, so that your stomach will expand. When you breathe out, the air in the balloon will also go out. Remember, we start by breathing out until all the air is out; then breathe in. If you can, try and breathe in through your nose and out through your mouth, that's the best.
- The second step is to slow the rate of your breathing. We are going to take three seconds to breathe in, then two seconds to hold your breath and three seconds to breathe out. I'll count with you. You may close your eyes or keep them open. So, breathe in, 1, 2, 3. Hold, 1, 2. And breathe out, 1, 2, 3. Did you notice how slowly I count? [Repeat this breathing exercise for approximately one minute].

Encourage practice at home: When you practice on your own, don't be too concerned about to keeping exactly to three seconds. Just try your best to slow your breathing when you are stressed.

BOX 11. PRACTICAL TIPS FOR HEALTH CARE PROFESSIONALS IN PROVIDING PSYCHOSOCIAL SUPPORT (124,125)

- Be aware of cultural differences and personal biases, and offer help in the most appropriate ways for the individual.
- Be aware of and respect people’s spiritual and religious background.
- Encourage people to do things that help them to cope, including spiritual routines, if they mention these.
- Don’t impose your beliefs or spiritual or religious interpretations of the outbreak or its complications on others.
- Don’t agree with or reject a spiritual belief or interpretation of the crisis, even if a person asks you to do so.
- Provide advice about basic self-care (nutrition, physical activity, safe sex, family planning), and help to arrange regular health assessments, vaccinations and access to assistive devices.
- When making a referral, help people to access the providers (e.g. provide directions to the location, operating hours, telephone number, or join them for the first appointment).




TABLE 9. STEPS IN MANAGING PROBLEMS

Step	Description
1. List problems	List the problems the person is experiencing, and together choose one to start with.
2. Define	Try not to include more than one problem. Ask the person to describe the issue and how it’s affecting him or her.
3. Discuss	Encourage the person to think of as many solutions to the problem as possible. Try to encourage the person to come up with ideas rather than giving solutions.
4. Prioritize	From the list of potential solutions, choose those that are most helpful and feasible. Helpful strategies have few disadvantages for the person or others. Help the person to choose the solutions he or she will try first, if there is more than one.
5. Plan for action	Discuss with the person how and when he or she will implement the solution. Discuss what resources (e.g. money, transport, a friend) the person might need to carry out the plan.

Source: Adapted from WHO Problem management+, reference 123

3.3



Management of severe conditions

Stress can be a severe condition in some people, and it is important both to identify the condition and to provide initial management. Management will involve both basic psychosocial interventions and more detailed treatment for the individual needs. (See section 3.2)   Referral to a mental health specialist should be considered. 

LEARNING OBJECTIVES

- ➔ *Be able to apply the general principles for management of depression.*
- ➔ *Be able to apply the general principles for management of substance use.*
- ➔ *Be able to apply the general principles of management of people at risk of self-harm and suicide.*

Management of depression

- Offer basic psychosocial support interventions as detailed above.
- Provide psychoeducation for the person and the family. Emphasize the following:
 - Depression is a very common condition that can happen to anybody; it does not mean that the person is weak or lazy.
 - Stigma or negative attitudes (e.g. “You should be stronger”, “Pull yourself together”) make it more difficult for people to speak openly about how they feel.
 - Even if they find it difficult, encourage people to do as many of the following as possible, as all can help to improve mood:
 - start again (or continue) activities that were previously pleasurable,
 - maintain regular sleeping and waking times,
 - be as physically active as possible,
 - eat regularly despite changes in appetite,
 - spend time with trusted friends and family and
 - participate in community and other social activities as much as possible.
- If trained, supervised therapists are available, consider referring people with moderate–severe depression. 
- Pharmacological interventions, such as antidepressants, should be avoided for pregnant and breastfeeding women if possible. If they do not respond to psychosocial interventions, refer them to a specialist  for prescription of antidepressants at only the lowest effective dose.

Management of substance use

Engage people in a discussion about their substance use. Ask, “What do you consider the benefits of taking this (substance)?” and “What might be the potential harm?” or “How does this behaviour affect you and the people you care about?”

Steer the discussion towards both the positive and the negative effects of the substance. Challenge overstated claims of benefits and mention some of the negative aspects, which are perhaps being understated.


Try to understand the real impact of the substance on the person’s life. Do not argue with the person but try to phrase a subject in a different way if it meets resistance. Encourage people to decide for themselves whether they want to change their pattern of substance use, particularly after a balanced discussion of the pros and cons of the current pattern of use.

If the person is still not ready to stop or reduce his or her substance use, ask the person to come back and discuss the problem further, perhaps with a family member or friend.

Health care professionals should advise pregnant and breast-feeding mothers that tobacco, alcohol and drugs should be avoided, because they are harmful for their babies. Substance abuse by women who are pregnant or breastfeeding is of specific concern.

- Inform women that drug use can interfere with their menstrual cycle, which may create the false impression that they cannot become pregnant.
- Pregnant women who are dependent on opioids should be advised to take an opioid agonist replacement, such as methadone. All infants born to mothers with suspected or known substance abuse should be screened for withdrawal symptoms, known as neonatal abstinence syndrome. This syndrome should be treated with low doses of opioids such as morphine or barbiturates.
- Advise and support breastfeeding mothers not to use psychoactive drugs.
- Advise and support mothers who have substance use disorders to breastfeed exclusively for at least the first 6 months, unless a specialist advises her not to.
- Mothers with harmful substance use and young children should be offered the social support services available, including additional postnatal visits, parenting training and child care during medical visits.

Management of self-harm and suicide (4)

- Identify any suicidal thoughts or suicide attempts. (See section 3.1.)  **3.1**
- A person who self-harms should be placed in a secure, supportive environment in a health facility and not left alone.
- If he or she has to wait for treatment, offer an environment that minimizes distress, if possible in a separate, quiet room with supervision and regular contact with a named staff member or a family member to ensure safety.
- Remove the means of self-harm.
- Consult a mental health specialist, if available.
- Mobilize family, friends and other concerned individuals or community resources to monitor and support the individual during the period of imminent risk. Provide emotional support to caregivers and family members if they need it.
- Treat people who have self-harmed with the same care, respect and privacy given to other people, and be sensitive to the probable emotional distress associated with self-harm. Encourage caregivers and families to avoid hostility or criticism towards people at risk of self-harm.

3.4

Specific considerations for people with Guillain Barré syndrome

People with GBS may face temporary difficulties in their daily activities, which may cause significant emotional distress. Stress in people affected by GBS, their caregivers and their families throughout the acute course of the illness, recovery and readjustment period can affect recovery if not recognized and addressed. Rarely, people with GBS have persistent difficulties in functioning, which require further psychosocial support and adjustment strategies.

LEARNING OBJECTIVES

- ➔ *Be aware that people affected by GBS and their caregivers and families might have different psychosocial stressors and reactions during the different stages of the disease.*
- ➔ *Become familiar with scientific information about GBS in order to respond to the needs of the affected person and the caregiver and family as they arise.*

The course of GBS is complex, with varying emotions during the different phases of the illness (Table 10). The affected people and their caregivers and family members frequently feel overwhelmed and uncertain about their health. They may feel fearful and anxious or numb and detached.

A number of factors contribute to a person's emotional response to their illness:

- the nature and severity of the symptoms,
- their experience of previous distressing events,
- the support they have from others,
- their general physical and mental health,
- their personal and family history of mental health problems,
- their cultural background and traditions,
- their perceptions of the medical profession and
- their age.

Acute phase

- In view of the sudden nature of this often debilitating illness, health care professionals should acknowledge and address the anger, fear and frustration of the people affected.
- Fear, grief and tension are likely to increase among caregivers and families. In these difficult moments, more than ever, it is essential to treat everybody with respect and contribute to an atmosphere of dignity for all.
- If the affected person is on a ventilator, they will not be able to communicate verbally, which may be very frustrating for them.

Plateau phase

- If the affected person is on a ventilator, they will not be able to communicate verbally, which can be very frustrating for them.
- Health care professionals should speak slowly and clearly and repeat information if necessary. Communication cards could be used.

Rehabilitation phase

- Maintain the general routine as much as possible. It is important to communicate to the affected person that he or she will probably recover to a point at which he or she can perform most if not all activities.
- Maintain rules and responsibilities, although revision of expectations may be required. Do not excuse a person recovering from GBS from responsibilities if he or she is capable.
- Involve friends, caregivers and family in the recovery.
- Stigma and discrimination can negatively affect psychosocial wellbeing and reintegration of people with GBS into their communities. Health and social care providers should contribute to dispelling myths about GBS.




For information on managing severe mental health conditions, including depression and suicide, see section 3.3.  **3.3**

TABLE 10. PSYCHOSOCIAL INTERVENTIONS BY PHASE OF ILLNESS IN GBS  

Phase	Relevant psychosocial interventions
Acute	<ul style="list-style-type: none"> • Supportive communication (see intervention A) • Identify and respond to needs and concerns (see intervention B) • Links to available social resources (see intervention C) • Discuss positive coping and stress reduction methods (see interventions D&E) • Consult a mental health professional
Plateau	<ul style="list-style-type: none"> • Supportive communication (see intervention A) • Discuss positive coping and stress reduction methods (see interventions D&E) • Links to available social resources (see intervention C) • Consult a mental health professional
Rehabilitation	<ul style="list-style-type: none"> • Discuss positive coping and stress reduction methods (see interventions D&E) • Assess severe conditions, and manage or refer as appropriate (see section 3.3)   • Provide links to available social resources (see intervention C) • Discuss alternative methods for dealing with problems (see intervention F) • Link with peer support groups in the community, if available • Consult a mental health professional

KEY MESSAGES

- ➔ *A wide range of psychosocial interventions can be used by health care professionals to support people affected by ZIKV and its complications in coping with stressors.*
- ➔ *At the primary care level, it is essential to assess for and provide mental health care and support to people affected by complications associated with ZIKV.*

LINKS TO RELEVANT RESOURCES

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of Zika virus: http://apps.who.int/iris/bitstream/10665/204492/1/WHO_ZIKV_MOC_16.6_eng.pdf?ua=1

mhGAP intervention guide for mental, neurological and substance use disorders in non- specialized health settings, Version 2.0: http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/.

mhGAP humanitarian intervention guide:

http://www.who.int/mental_health/publications/mhgap_hig/en/

Thinking healthy: a manual for psychological management of perinatal depression:

http://www.who.int/mental_health/maternal-child/thinking_healthy/en/

Problem management plus (PM+) Individual psychological help for adults impaired by distress in communities exposed to adversity: http://www.who.int/mental_health/emergencies/problem_management_plus/en/

Group interpersonal therapy for depression:

http://www.who.int/mental_health/mhgap/interpersonal_therapy/en/

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**WHO TOOLKIT FOR THE CARE AND SUPPORT OF PEOPLE
AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS**

Manual for health care professionals

This manual is designed to build capacity of the health care professionals who provide care and support for people affected by complications associated with Zika virus, both children and adults, as well as their caregivers and families in primary care facilities. The manual prepares health care professionals with the tools they need to assess and manage complications, including addressing physical and psychological health.

The manual contains the following modules:

1. Management of children born in Zika virus-affected areas
2. Assessment and management of people with Guillain Barré syndrome and other neurological complications triggered by Zika virus
3. Mental health and psychosocial support for people affected by complications associated with Zika virus

For information required to coordinate care and support for people affected by complications associated with Zika virus refer to the Manual for public health planners and managers. ➡  Practical guidance on delivering comprehensive, long-term community based care can be found in the Manual for community workers. ➡ 

**WHO TOOLKIT FOR THE CARE AND SUPPORT
OF PEOPLE AFFECTED BY COMPLICATIONS
ASSOCIATED WITH ZIKA VIRUS**

Manual for community workers



**World Health
Organization**



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This manual is designed mainly for workers in the communities of people who are affected or at risk of complications associated with Zika virus. Comprehensive, long-term community care for affected people should include: ensuring access to routine health and social care services, support for additional, specific health needs, promotion of early childhood development and interventions for children with developmental disabilities as part of congenital Zika virus syndrome, rehabilitation for individuals with Guillain Barré syndrome and other neurological complications and mental health and psychosocial support, including for families and caregivers.

Throughout this manual, the terms “caregiver” and “family” are used to refer to the primary sources of care and support for people affected by complications associated with ZIKV. They include both formal and informal caregivers in the community. Families are an important unit in the care and support of both children and adults affected by complications associated with ZIKV. The constitution of a family may differ by context, comprising not only parents or partners but also siblings, grandparents and extended family members.

MODULE 1

Providing care and support for children in a Zika virus-affected area

- 1.1 *Supportive communication*
- 1.2 *Monitoring and following up children with or at risk for congenital Zika virus syndrome for health and development difficulties*
- 1.3 *Promoting and supporting the development of children with or at risk for congenital Zika virus syndrome*

MODULE 2

Psychosocial support for caregivers and families of children with or at risk for congenital Zika virus syndrome

- 2.1 *Common reactions and assessment of mental health and psychosocial needs*
- 2.2 *Providing psychosocial support and facilitating a peer support group*
- 2.3 *Management of severe conditions*

MODULE 3

Rehabilitation and psychosocial support for people affected by Guillain Barré syndrome triggered by Zika virus


- 3.1 *Overview of Guillain Barré syndrome and stages in rehabilitation in the community and at home*
- 3.2 *Preparing a plan for rehabilitation in the community and at home*
- 3.3 *Rehabilitation interventions*
- 3.4 *Psychosocial support*

The role of community workers

Responding to Zika virus (ZIKV) and preparing control and preventive measures require community knowledge and expertise, building on local capacity and strengthening the available resources. Community workers are essential human resources in the response to ZIKV, for identifying and assessing children and families at risk, providing acute and long-term care and support, and monitoring progress or relapse/decline in community-based settings.

The term “community workers” is used to refer to a diverse group of lay and formally educated, formally and informally assigned, paid and unpaid workers in the health, social care and education sectors.


Purpose of the manual

This manual provides practical guidance for mainstreaming care and support for people affected by complications associated with ZIKV into existing health and social care services. The manual should be used with the other elements of the WHO Toolkit for the care and support of people affected by complications associated with ZIKV. For care to be well coordinated, community workers should work in partnership with other providers in the community and in facilities. Community workers should know when and how to refer children for additional assessment and further support in the community and other service levels.* 

Target audience

The manual targets community workers in all countries that have reported vector-borne ZIKV transmission and also in countries at risk for ZIKV transmission who directly care for people affected by complications of ZIKV. It is designed to build their capacity to deliver coordinated care.

Module 1 provides guidance in delivering comprehensive, long-term community follow-up care for children with congenital Zika virus syndrome (CZVS) and their families. The care includes ensuring access to routine health services, addressing additional health needs (e.g. feeding difficulties, irritability, seizures), monitoring development (including hearing and vision), promoting early child development and providing additional developmental support (including early intervention and/or rehabilitation) when needed.

Module 2 describes the role of community workers in meeting the mental health and psychosocial needs of families and caregivers affected by complications associated with ZIKV. The module provides guidance for assessing common reactions to the increased stress and challenges faced by families and caregivers, for providing relevant interventions to support families and caregivers in the community and for deciding when to refer them to mental health specialists or other services in the local community. 

Module 3 provides practical guidance for community workers in caring for and supporting people affected by Guillain Barré syndrome (GBS) triggered by ZIKV through community-based rehabilitation and psychosocial support.

Table 1 outlines the information that will be acquired by community workers in this manual.

*Throughout the text, presentations that should trigger referral to a higher level are indicated by 

TABLE 1. LEARNING OUTCOMES FOR COMMUNITY WORKERS

Section	Topic and description	By the end of this section, community workers will be able to:
Module 1. Providing care and support for children in a Zika virus-affected area		
1.1	Supportive communication	<ul style="list-style-type: none"> recognize the role of supportive communication for families and caregivers of children affected by CZVS; and identify barriers, facilitators and strategies to communicate effectively.
1.2	Monitoring and following up children with or at risk for CZVS for health and developmental difficulties	<ul style="list-style-type: none"> be familiar with the range of ways in which CZVS can affect children's health, learning and development; manage, monitor and respond to concerns about a child's development; and know when to refer children with or at risk for CZVS to a higher level.
1.3	Promoting and supporting the development of children with or at risk for CZVS	<ul style="list-style-type: none"> understand their role in providing targeted support for children with developmental difficulties as a result of CZVS; consider how the strategies could be adapted for children with developmental difficulties and/or disabilities; and know when to refer and how to link families with broader support services; and coordinate follow-up care.
Module 2: Psychosocial support for caregivers and families of children affected by CZVS		
2.1	Common reactions and assessment of mental health and psychosocial needs	<ul style="list-style-type: none"> recognize the stressors that face parents of children with CZVS and other complications associated with ZIKV; and assess families and caregivers for common mental health and psychosocial needs and know when to refer them to a specialist.
2.2	Providing psychosocial interventions and facilitating a peer support group	<ul style="list-style-type: none"> provide effective psychosocial interventions for people affected by complications associated with ZIKV; link families and caregivers to available community resources and multidisciplinary care; and facilitate peer support groups for families and caregivers to engage and learn from one another.
2.3	Management of severe conditions	<ul style="list-style-type: none"> assess when someone is feeling very low mood or sad or misusing alcohol or other substances; identify people at risk of self-harm or suicide; and know when to refer a person to a mental health specialist for further management.
Module 3: Rehabilitation and psychosocial support for people with Guillain Barré syndrome triggered by ZIKV		
3.1	Overview of GBS and stages in rehabilitation in the community and at home	<ul style="list-style-type: none"> understand the common experiences and challenges of people with GBS; and understand the basic steps in planning an individual rehabilitation programme.
3.2	Preparing a plan for rehabilitation in the community and at home	<ul style="list-style-type: none"> identify the components to be assessed before preparing a rehabilitation programme and recognize the importance of including the individual and family members in preparation of an effective treatment programme.
3.3	Rehabilitation interventions	<ul style="list-style-type: none"> be aware of the main interventions for improving mobility, functioning, daily living, swallowing, speech, pain and fatigue; know the steps involved in preparing people to return to school, job and/or community activities; and decide how long to continue rehabilitation.
3.4	Psychosocial support	<ul style="list-style-type: none"> be aware of the psychosocial stressors and reactions during various stages of GBS; and identify warning features of severe mental health conditions that require consultation or referral to a mental health professional.

1

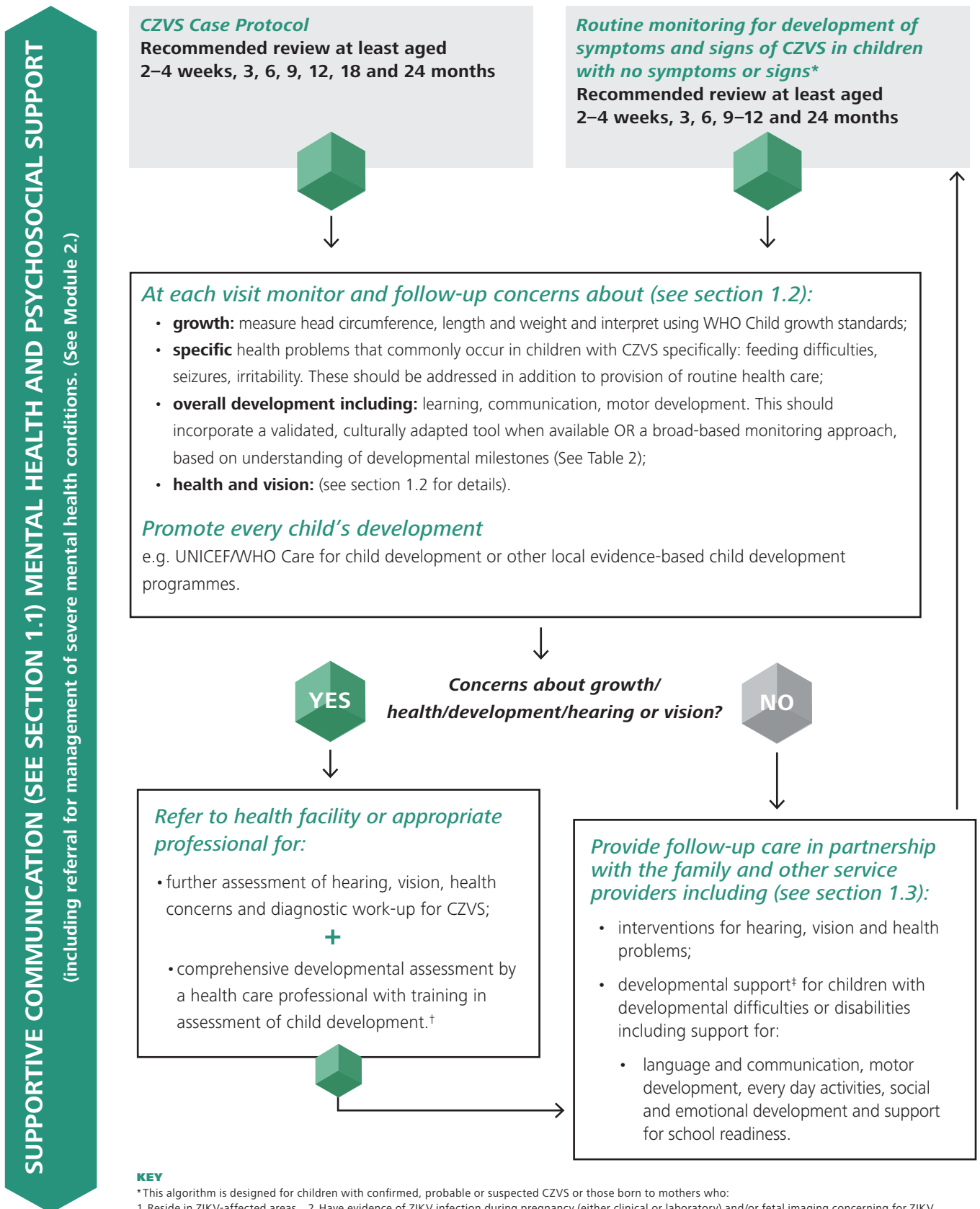
MODULE

Providing care and support for children in a Zika virus- affected area

The aim of this module is to provide guidance on care in the community for children with or at risk for complications due to congenital exposure to ZIKV. This module is designed to be used in conjunction with module 2, which addresses psychosocial support.

- 1.1** *Supportive communication*
- 1.2** *Monitoring and following up children with or at risk for congenital Zika virus syndrome for health and development difficulties*
- 1.3** *Promoting and supporting the development of children with or at risk for congenital Zika virus syndrome*

FIG 1. COMMUNITY FOLLOW-UP FOR INFANTS AND YOUNG CHILDREN WITH OR AT RISK FOR CONGENITAL ZIKA VIRUS SYNDROME (CZVS)



KEY

* This algorithm is designed for children with confirmed, probable or suspected CZVS or those born to mothers who:

1. Reside in ZIKV-affected areas 2. Have evidence of ZIKV infection during pregnancy (either clinical or laboratory) and/or fetal imaging concerning for ZIKV infection

† Where possible, comprehensive developmental assessment should be undertaken by a multidisciplinary team and should include a structured, validated and appropriate developmental assessment instrument. ‡ “Developmental support” here refers to a range of strategies used to improve the child’s development, functioning and/or participation in family and community life as well as reducing secondary health and developmental problems wherever possible. This is sometimes also referred to as “early intervention” and overlaps with rehabilitation in children.

TABLE 2. STEPS IN FOLLOWING UP CHILDREN WITH OR AT RISK FOR CZVS

Visit	Items to be evaluated	Vision monitoring (1, 2)
Initial (within first 2 weeks of life)	<ul style="list-style-type: none"> Assess growth: measure head circumference, length and weight; interpret measurements with WHO child growth standards. In addition to providing routine health care for all children, check for: <ul style="list-style-type: none"> – feeding difficulties; – seizures or abnormal movements; and – irritability Check development with a validated, culturally appropriate (if available) or broad monitoring approach based on developmental milestones. Check hearing and vision (See Vision and hearing assessment for details.) 	<ul style="list-style-type: none"> Assess reactions to light and faces. Does the infant blink when a bright light is flashed in his or her eyes? Does the infant turn to a diffuse light, such as a light coming from a window? (by 6 weeks)
3 months		<ul style="list-style-type: none"> Eye examination by a specialist (i.e. an ophthalmologist) if possible. Ask families and caregivers whether they have any concern about their child’s vision. Look for any abnormal eye movements or alignment. Does the infant look at your face when 10–20 cm away? Does the infant respond to silent smiles or eyebrow raising? Does the infant fix on and follow a dangling ball or toy?
6 months		<ul style="list-style-type: none"> Ask families and caregivers whether they have any concern about their child’s vision. Look for any abnormal eye movements or alignment. <p>By 4 months:</p> <ul style="list-style-type: none"> Does the infant watch an adult 1.5m away? Do the infant’s eyes converge properly (If you move a toy closer and further away, do the eyes focus on the toy and line up properly?). <p>By 5 months:</p> <ul style="list-style-type: none"> Does the infant blink in response to a threat (any silent, sudden movement close to the face that causes no breeze, e.g. opening your fist very suddenly)?
9–12 months*		<p>From 1–5 years:</p> <ul style="list-style-type: none"> Ask families and caregivers whether they have any concern about their child’s vision. Look for any abnormal eye movements or alignment. Children should show interest in colourful, interesting objects around them. They should respond to silent smiles, eyebrow raising and winking. They should be able to see objects in their peripheral visual field. They should be able to identify different sized objects with each eye while the other eye is covered.
24 months*		

* For confirmed, probable or suspected cases of CZVS, follow the CZVS case protocol, with suggested visits at least 9, 12, 18 and 24 months.

‡“Developmental support” here refers to a range of strategies that may be used to improve the child’s participation in family and community life as well as reducing secondary health and developmental problems when possible. This is sometimes referred to as “early intervention” and overlaps with rehabilitation.

Hearing monitoring (3)	Actions	Mental health and psychosocial support (See also Module 2)
<ul style="list-style-type: none"> • Behavioural evaluation: infant should show some sign of hearing sounds, e.g. open the eyes, blink and look alert. • If available, a physiological hearing screen (automated auditory brainstem response or otoacoustic emissions test) should be performed, if it was not done at birth. 	<p>All children:</p> <ul style="list-style-type: none"> • Promote every child’s development e.g. through UNICEF/WHO Care for child development or other local evidence-based child development programmes. <p>For children with confirmed, probable or suspected CZVS or for whom there is concern about growth, health, development, vision or hearing:</p> <ul style="list-style-type: none"> • Refer for detailed assessment including: <ul style="list-style-type: none"> • diagnostic assessment of hearing and/or vision; • review by a health professional; • diagnostic work-up for CZVS (e.g. neuroimaging, ZIKV testing); and • comprehensive developmental assessment. • The assessment should include review by a health care professional with appropriate training in assessing child development and ideally by a multidisciplinary team. • Develop a management and follow-up plan with the family and other service providers, including: <ul style="list-style-type: none"> • interventions for hearing, vision and health problems; • inclusion of children with CZVS in routine programmes to promote child development; and • target developmental support for children with developmental difficulties.‡ 	<ul style="list-style-type: none"> • Use supportive communication techniques to discuss the child’s development with the parents. • Encourage interaction with the child, emphasizing the importance of environmental stimulation for optimal development. • Recognize that parents of children born in areas severely affected by ZIKV may be experiencing stress, even if the child appears well. • Continue to support the parents or caregiver in stress management when appropriate, and encourage the caregiver to take periods of respite. • Use the interventions described in Module 2 to help care and support families and caregivers who are experiencing mild to moderate distress. • If available, provide information on parent support groups and similar resources. • A parent or caregiver who shows signs of severe distress affecting their day-to-day tasks and activities for more than 2 weeks should be referred to a mental health professional.
<ul style="list-style-type: none"> • Behavioural evaluation: infant should respond by trying to see where a sound is coming from by turning his or her head or eyes in the direction of the sound. 		
<ul style="list-style-type: none"> • Behavioural evaluation: infants should be hearing loud and very soft sounds and making many sounds themselves; by 12 months, they should respond to their name and other words. • Perform repeated physiological hearing tests (automated auditory brainstem response or otoacoustic emissions). 		
<ul style="list-style-type: none"> • Behavioural evaluation: ask parents whether the child appears to hear normally even when spoken to very softly; assess whether the child has appropriate language development (starting to put together words and has a vocabulary of > 10 words at a minimum). 		



Supportive communication

Supportive communication by community workers is an important part of follow-up care for children and families affected by CZVS.

LEARNING OBJECTIVES

- ➔ *Recognize the role of supportive communication in caring for and supporting families and caregivers of children affected by CZVS.*
- ➔ *Identify barriers, facilitators and strategies for effective communication with families of children with CZVS.*

Supportive communication techniques for use with children affected by CZVS are also discussed in section 1.3. ➔ 

General communication tips (6)

- **Create an environment that facilitates open communication: be welcoming, and introduce yourself in a culturally appropriate manner;**

- Where possible, identify a quiet, private space with minimal distractions in which the person can share his or her feelings and concerns.
- Do not interrupt or rush the person while he or she is speaking (avoid interrupting, speaking rapidly, looking at your watch).
- Explain that the discussions during visits are kept confidential.
- Maintain eye contact, and use body language and facial expressions that engender trust without judgement.

- **Listen.**

- Remember that people affected by complications associated with ZIKV may feel confused, upset, angry and frightened.
- Use simple language and stay calm, even when parents or caregivers are acutely distressed; this makes them feel respected and empowered.
- Acknowledge their feelings and reassure them that stress and grief are common reactions in such difficult situations.
- Do not judge their feelings; avoid saying "You should not feel that way."
- Acknowledge the coping mechanisms and methods they use to reduce stress.
- Allow them to remain silent.

- **Be respectful, supportive and provide accurate information.**




- Be non-judgemental when providing advice to counter negative coping mechanisms, especially those with an adverse effect on the person or family.
- Be sensitive to cultural differences and perceptions; be aware of and set aside your own biases and prejudices.
- Provide families with accurate, up-to-date sources of information.

- **Deliver information clearly.**

- Use non-technical language.
- Encourage questions.
- Summarize and repeat key points.

- **Recognize your own needs. When you need it, take a break until you can effectively provide supportive communication.**

When working with children with CZVS and their families, it is also important to:

- Include the child in visits whenever possible, and be responsive to their developmental and communication abilities.
- Encourage families and caregivers to ask questions and define their priorities. As children's and families' needs change over time, support should address the current situation.
- Make sure that families understand the purpose of community follow-up visits and the role of different service providers in supporting them and their child.
- Make sure the family knows how to access support between scheduled visits if necessary.
- Explain your role in supporting families and caregivers more broadly, when appropriate. (See also Module 3.)  
- Know when to refer a family member or caregiver to a health care professional. 

KEY MESSAGES

- ➔ *Having a child with CZVS has broad implications for the child and also for his or her family and caregiver.*
- ➔ *Community workers can help families and caregivers to adapt and respond to the changing care needs of their child.*
- ➔ *Supportive communication can help in overcoming barriers to access and improve the care of children with CZVS.*
- ➔ *Community workers should understand the principles of effective communication in order to respond to the needs of children, families and caregivers.*




Monitoring and following up children with or at risk for CZVS for health and developmental difficulties






CZVS is a constellation of neurodevelopmental signs and symptoms associated with ZIKV infection during pregnancy. The syndrome includes brain malformations, seizures, irritability, difficulty in swallowing, limb contractures and hearing and sight abnormalities. Not all children with CZVS have microcephaly (i.e. a head much smaller than those of other children of the same age and sex), and not all features of the syndrome may be evident at birth (7).

Long-term community care of children with CZVS is important for monitoring and optimizing growth, health and development. Comprehensive long-term management is multidisciplinary and includes access to routine health services, support for additional health needs, developmental monitoring, early child development programmes, early intervention or rehabilitation and mental health and psychosocial support. As children grow, preparation for school and inclusive education programmes must also be considered.

LEARNING OBJECTIVES



- ➔ *Become familiar with the ways in which CZVS can affect children's health, learning and development.*
- ➔ *Understand the role of different service providers in follow-up care for children with or at risk for CZVS.*
- ➔ *Understand the management of common health conditions in these children, including;*
 - *growth,*
 - *feeding difficulties,*
 - *muscle tone,*
 - *irritability,*
 - *seizures,*
 - *bone and joint problems, and*
 - *drooling.*
- ➔ *Know when to refer children with or at risk for CZVS for health or growth problems.* 
- ➔ *Be able to monitor and respond to concerns about a child's development, including hearing and vision.*
- ➔ *Consider the role and responsibility of community workers in recognizing and responding to concern about abuse or neglect in children with or at risk for CZVS.*

What should be checked at each visit

- Growth, including measurement of the head circumference, length and weight (8) and interpreting the measurements according to the WHO child growth standards (9) **(Box 1)**.
- Health, including asking about and addressing health problems that occur more commonly in children with CZVS, including difficulty in feeding, seizures or abnormal movements and irritability. Provide routine health care, including checks for danger signs and preventing and responding to acute illness (10).
- Development, including checking a child's overall learning, communication, motor development and wellbeing as well as their hearing and vision. (See Monitoring hearing and vision, page 24 and Monitoring the development of children with or at risk for CZVS, page 22). The children's development should be promoted by supportive caregiving (See Strategies to promote every child's development, page 29).
- Referral of children with health or development problems, including hearing and vision.  These children require further assessment of health, hearing and vision, comprehensive developmental assessment and further investigation of CZVS, depending on the issue identified and the local service structure. (See section 1.3.)  **1.3**
- Mental health and psychosocial needs, including asking about stressors, the duration and severity of symptoms, coping strategies and available social support. (See section 2.1 and Module 3.)  **2.1**  **3**
- Work in partnership with families and other service providers to prepare a management and follow-up plan for children in whom problems or developmental difficulties have been identified. (See section 1.3.)  **1.3**

Growth, nutrition and feeding

Growth monitoring

- Check children's growth, including head circumference, length and weight (8), at each visit and interpret the results with WHO child growth standards (9) (Box 1).
-  Refer children with slow or accelerated head growth for further assessment, investigation and management for the cause, including for ZIKV (See the Manual for health care professionals.) 
- Monitor the child's weight or length according to the usual growth monitoring protocols (e.g. integrated management of childhood illness, 11).

BOX 1. MEASURING HEAD CIRCUMFERENCE (8)

1. Anchor tape over eyebrows.
2. Pass tape over fullest part at the back of the head.
3. Check correct positioning.
4. Pull tight.
5. Record head circumference (cm) to last completed 1 mm.




Nutrition and feeding


Children with CZVS commonly have difficulty in feeding due to a number of factors, which can result in slow feeding and reduced intake. This can result in poor health for the child and is stressful for families and caregivers.

Community workers should teach and encourage parents to consider the environment and hygiene when feeding their child, especially hand-washing and feeding in a place where there are as few distractions as possible.

They should advise families and caregivers to feed infants with or at risk for CZVS according to standard recommended infant feeding guidelines (12, 13). Children should:

- start breastfeeding within 1 h of birth,
- be exclusively breastfed for 6 months,
- receive adequate, safe complementary foods when ready and
- continue breastfeeding to 2 years of age or beyond (13).
- The mother should ensure good positioning to make feeding easier and safer.
- Utensils: Families and caregivers should use utensils that are appropriate for the child at different ages and stages and will support feeding.
- Food textures: Children with feeding and swallowing difficulties may not be able to swallow foods with certain textures that other children of similar age can swallow. Caregivers should be given strategies to monitor and adjust the consistency of food and drinks to make sure that their child can swallow them.
- Encourage responsive feeding. More time and patience may be required to feed children with feeding and swallowing difficulties. Encourage parents to identify and respond to their child's cues and communication on feeding.
- Monitor the children carefully for feeding difficulties that are more common in children with CZVS (e.g. difficulty in swallowing, constipation and/or reflux) (14).


- Respond to concerns about feeding or growth, which may include additional support by appropriately trained community workers or require referral to specialist services  (e.g. speech and language therapists and dieticians), depending on local services. Use strategies to support children with or at risk for CZVS who have feeding difficulties including:
 - positioning, adjusting the rate, ensuring that their food is rich in energy, the thickness and texture of food, the frequency of feeding and alternative feeding utensils;
 - caloric supplementation if weight gain is poor, with additional feeds, complementary foods rich in vitamins and nutrients and general nutritional counselling (15);
 - fortification of feeds with micronutrients; iron and additional supplements appropriate for age and risk factors should be added according to WHO guidance (15); and
 - ensuring appropriate vitamin D and calcium intake, given that children with CZVS may have a number of risk factors for poor bone health (15).
 - Resources for community workers to understand how to inform and support parents in feeding their children are listed at the end of this module.

Some children will have substantial feeding difficulties in spite of these strategies. These children should be referred to a health facility for further assessment and support  (Box 2).

BOX 2. REFER A CHILD WITH FEEDING DIFFICULTIES TO A HEALTH FACILITY, IF (10):


- growth or nutritional status is of concern;
- hydration is of concern;
- difficulty is found in initiating or sustaining breastfeeding or other oral feeding;
- the child has respiratory problems;
- the child has persistent distress during feeding; or
- the child presents with recurrent vomiting.

Drooling (16)

Children with CZVS may drool, due to factors such as abnormal muscle tone and coordination in the mouth, tongue and swallowing muscles, positioning, seizures, reflux, dental problems and medication. Drooling can affect health, by increasing the risk for chest infections, and is sometimes a cause for stigma. When possible, refer children who drool for multidisciplinary care, including review by a health professional, dentist, speech and occupational therapist, to prepare a management plan.  When this is not possible, community workers can consult various resources to find common treatments approaches. (See Links to relevant resources at the end of the module.)

Muscle tone management (7, 16)

Children with CZVS may have abnormal muscle tone, i.e. unusually stiff or floppy muscles or both. Abnormal tone can be an early sign of CZVS but may be difficult to assess. The Links to relevant resources at the end of the module will assist community workers in understanding how to assess tone in infants and young children.






Treatment of abnormal tone is important for joint movement and to prevent pain and contractures (i.e. shortening of muscles and tendons that can lead to joint deformities). Refer children with abnormal muscle tone to a health facility for further assessment and treatment.  When this is not possible, community workers can use common treatments, including:

- physical therapy and stretching,
- orthotics (i.e. braces and devices to support positioning of the body),
- positioning and
- mobility and assistive devices.

See Links to relevant resources at the end of the module.

Irritability, prolonged crying and sleep difficulties (7, 17)

Otherwise well, typically developing infants show a wide range of normal crying, fussing and sleep patterns. Children with CZVS are commonly irritable, sometimes severely so, and may not respond to normal soothing strategies. Many factors may contribute to irritability in a child with CZVS, including infections, difficulties in feeding and digestion, seizures and other central nervous system effects (e.g. hydrocephalus), bone and joint problems including fractures, dental disease, eye problems, medication, poor sleep, non-accidental injury, changes in the home environment and emotional distress.

- Encourage families and caregivers to recognize and respond to unsettled behaviour in their infant or child. (See also section 1.3.)  
- Encourage parents of children with CZVS to try the usual strategies for settling an infant, and observe what works and when. Simple strategies include gentle rocking, massage, carrying, a warm bath, playing music or speaking or singing softly.
- Refer children who present with persistent or severe irritability to a health professional  for assessment and a more detailed management plan, as there are many potential medical causes of excessive irritability, crying and sleep disturbance among children with CZVS.
- Community workers should make sure they understand the plan for follow-up and review of each child after medical review, in close communication with referral facilities.
- Provide broader support to help parents and families manage their own stress, and monitor maternal and family wellbeing, because irritability in infants and young children can affect the whole family. (See Module 3.)  
- Community workers should advise family members that (17):
 - if they themselves feel they are becoming irritable, they should place the infant or child in a safe place and take time to become calmer before resuming care;
 - an infant or child should never be shaken, as this can cause bleeding inside the brain and permanent brain damage; and
 - it is important to seek help when an infant cries for long periods, is difficult to soothe or does not settle readily to sleep.


Seizures (4)

Epilepsy (repeated fits, convulsions or seizures) is a common medical condition in children with CZVS, and parents and caregivers should be told that seizures are not contagious or caused by spirit possession, witchcraft or the sins of the child's family or ancestors. Early identification and treatment are important because seizures can interfere with learning, health and wellbeing.

Community workers should suspect seizures in any child with:

- episodes of decreased responsiveness,
- abnormal repetitive movements and
- loss of developmental skills at any age.

They should refer any child with suspected seizures to an appropriate facility for further assessment and treatment.

 In many cases, seizures can be treated effectively with medicine. When a child has been prescribed medications by a health care professional, these should be ceased only on the advice of a health care professional. Stopping medication for seizures (i.e. anti-epileptic drugs) abruptly can worsen seizures.


Children with epilepsy are not a danger to other children and should not be prevented from playing with other children or from going to school.


Care that can be provided for children with seizures is shown in **Fig. 2** and **boxes 3 and 4**.

Bone and joint problems (7)

Normal muscle tone and strength are important for healthy growth and development of joints.

Children with CZVS may have bone and joint difficulties, such as hip problems and joint contractures (tightening and shortening of muscles) with deformity of the joint. These problems may be present at birth or may develop over time, especially in children with poor mobility.

Appropriate positioning and access to services such as physiotherapy, if possible, can reduce the risk for additional bone and joint problems in children with delayed motor development or motor disabilities. (See section 1.3.) 

Refer children with problems of tone, mobility or joints to an appropriate facility for further assessment and treatment. 

BOX 3. IF YOU SEE A CHILD HAVING A SEIZURE, TAKE THE FOLLOWING STEPS (4,9, 16)

- Protect the child from injury by making sure they are in a safe place, away from fire or other things that might injure them.
- Put the child on his or her side when possible, with the head turned to help breathing.
- Make sure the child is breathing.
- Bring or call nearest health care professional in the case of: breathing difficulty, seizure lasts longer than 5 min, or child does not wake up after the seizure.
- Stay with the child until the seizure stops and he or she wakes up;
- Do not put anything into the child's mouth.
- Do not hold the child down during the seizure.

FIG 2. SEIZURE RESCUE POSITION

Source: mhGAP Humanitarian Intervention Guide (18)

BOX 4. INFANTILE SPASMS

These are a particular type of seizure that commonly occur in children with CZVS, usually during the first year of life (usually 3–6 months) and is a medical emergency that requires specialized treatment.

“Spasms” are sudden contractions of the body and limbs, which generally affect both sides of the body and occur in clusters, often occur as the infant wakes, sometimes with an associated cry, although they can occur in any state.

This type of seizure is commonly associated with loss of developmental skills.

Refer any child with suspected infantile spasms to a health professional for assessment and treatment.

Development (7, 10)


The learning and development of children with CZVS are affected by their exposure to ZIKV before they were born. CZVS can affect children's brains, vision and hearing development. This affects the way children interact, explore and learn from the world around them.

During development, children's motor, cognitive, communication and social-emotional skills emerge through a series of milestones or stages. Much of what children learn, they learn when they are very young. Children play an active role in their own development, and their development is influenced by interactions with people, especially their families and caregivers and their environment. Children need consistent loving attention from at least one person and a safe environment as they learn.

Each child with CZVS is a unique individual with a range of abilities and challenges. Understanding each child's needs and abilities is important to enable them to access additional support in a timely way. Developmental support in the community helps each child reach his or her individual potential, have the best possible quality of life and participate in the family and the community.

Monitoring the development of children with or at risk for CZVS (19)

Developmental monitoring includes visiting the child and the family regularly and following the child's development in all areas (cognitive, language, social-emotional and motor development). This should be done with a validated, structured, culturally adapted tool when available. If no appropriate tools are available, a broad monitoring approach based on developmental milestones should be used (Table 3).

- Parents' concern about their child's development is important and should be followed up. Families and caregivers should be considered active partners in monitoring.
- Screen for other identifiable and treatable conditions (e.g. hearing and vision problems), which also affect child development.
- Refer children for further assessment and additional support when developmental monitoring indicates a problem. 

Children with CZVS may have abnormal tone, i.e. unusually stiff or floppy muscles or a combination. Abnormal tone may be an early sign of CZVS but may be difficult to assess. See the Links to relevant resources below for information to support community workers in knowing and understanding how to assess tone in infants and young children.

TABLE 3. CHILD (0–3 YEARS) DEVELOPMENT, EXPECTED PROGRESS AND CONCERNS THAT SHOULD PROMPT FURTHER ASSESSMENT AND REFERRAL

Age	Developmental needs	Expected progress	Findings that should prompt further assessment and referral)*
Birth to 3 months	<ul style="list-style-type: none"> • Protection from danger • Adequate nutrition • Access to routine health care, including vaccination • Responsive care and parenting, including appropriate language stimulation and motor and sensory stimulation 	<ul style="list-style-type: none"> • Begin to smile • Track people and objects with their eyes • Prefer faces and bright colours • Turn toward sound • Discover feet and hands 	<ul style="list-style-type: none"> • Poor sucking or difficulty in feeding • Abnormal movement of arms or legs† • Little or no reaction to loud sounds • Little or no reaction to bright lights • Excessive irritability

Age	Developmental needs	Expected progress	Findings that should prompt further assessment and referral)*
4–6 months	<ul style="list-style-type: none"> • Protection from danger • Adequate nutrition • Access to routine health care, including vaccination • Responsive care and parenting, including appropriate language stimulation and motor and sensory stimulation 	<ul style="list-style-type: none"> • Smile • Develop preferences, generally for parents and older siblings • Repeat actions, with interesting results • Listen intently • Respond when spoken to • Laugh and gurgle • Imitate sounds • Explore hands and feet • Put objects in mouth • Sit when propped • Roll over • Grasp objects without using thumb 	<ul style="list-style-type: none"> • Abnormal movement of arms or legs[†] • Do not smile in reaction to parent or caregiver (4 months) • Abnormal eye movements or alignment • Do not turn towards sound
7–12 months	<ul style="list-style-type: none"> • Protection from danger • Adequate nutrition • Access to routine health care, including vaccination • Responsive care and parenting, including appropriate language stimulation and motor and sensory stimulation 	<ul style="list-style-type: none"> • Remember simple events • Identify themselves, body parts and familiar voices • Understand their name and common words • Say first meaningful words • Explore objects and find hidden objects • Put objects in containers • Sit alone • Pull themselves up to stand and walk 	<ul style="list-style-type: none"> • Abnormal movement of arms or legs[†] • Shows early hand preference (< 12 months) • Cannot sit without support by 10 months • Do not respond to caregiver • Do not make sounds in response to others • Do not look at moving objects • Abnormal eye movement • Abnormal eye alignment
1–2 years	<ul style="list-style-type: none"> • Protection from danger • Adequate nutrition • Access to routine health care, including vaccination • Development of motor, language and thinking skills • Development of independence • Learn self-control • Opportunities for play with other children 	<ul style="list-style-type: none"> • Imitate adult actions • Speak, and understand words and ideas • Experiment with objects • Walk steadily, climb stairs and run • Recognize ownership of objects • Form friendships • Solve problems • Show pride in accomplishments • Begin make-believe 	<ul style="list-style-type: none"> • Abnormal movement of arms or legs[†] • Shows early hand preference (< 12 months) • Cannot walk alone (18 months) • Do not respond to others • No single words by 20 months • Do not use gestures such as pointing, shaking head or other movements to indicate what they want (18 months) • Parental concern about vision • Abnormal eye movement or eye alignment
2–3.5 years	<ul style="list-style-type: none"> • Protection from danger • Adequate nutrition • Access to routine health care, including vaccination • Make choices • Opportunities for dramatic play • Read increasingly complex books to the child • Sing favourite songs • Pose simple puzzles 	<ul style="list-style-type: none"> • Enjoy learning new skills • Learn language rapidly • Gain increasing control of hands and fingers • Act more independently 	<ul style="list-style-type: none"> • Abnormal movement of arms or legs[†] • Fall frequently • Persistently walk on the toes • Have difficulty in manipulating small objects • Unable to follow a simple spoken command or direction (without gestures) (2 years) • Cannot say even several words (e.g. "mama go", "give dada") (2.5 years) • Abnormal eye movement or eye alignment • Parental concern about hearing or vision

* Warning signs – based on upper limit of expected age for attainment of developmental milestone or presence of a symptom or sign that should prompt further assessment and/or referral. Use corrected age for preterm infants. Loss of previously attained developmental skills (i.e. regression) should also prompt further assessment and/or referral. Parents' concerns about their child's development are always important and should be followed up.

† Abnormal movement of the arms and/or legs – this may include asymmetrical movement (uneven from side to side) and lack of or uncontrolled movement. In infants, asymmetrical movement may be evident as early (<12 month) development of a hand preference. In children who can walk, an uneven or unusual gait, which may be seen only on running, may indicate asymmetry.

Monitoring hearing and vision (3, 7, 20, 21)

Hearing

Children with or at risk for CZVS are at more likely to have hearing difficulties, which may not be detectable at birth. Community follow-up to identify and provide additional support for hearing problems in these children is important.


- Good hearing is important for speech and language development.
- Good speech and hearing are important for communication.
- Good communication is important for learning at home and at school.

Delays in development in other domains may reflect hearing problems. For example, children who show delayed language or social skills should be referred for a hearing assessment. Early identification of hearing impairment, with support and early intervention, can improve residual hearing and the developmental outcomes for affected children.


Community workers can monitor children's hearing in various ways. In infants and young children, objective screening tests such as otoacoustic emissions, which require training and equipment, are preferred. Objective testing is more reliable than clinical or behavioural methods such as distraction tests; however, when objective methods are not available, resources such as the WHO Primary ear and hearing care training manual (3) provide information on behavioural hearing testing methods for community workers (Table 4).

Vision

The vision of children with CZVS can be affected in various ways. Children with and without microcephaly may have eye diseases.

Delays in development in other domains may reflect underlying visual problems. For example, children who present with delays in fine motor development should be referred for visual assessment. 

Community workers should review children for visual problems at each routine visit (Table 4).

Refer children with hearing or vision problems,  so that the child or his or her family can be:

- advised and informed appropriately;
- given a formal vision or hearing assessment;
- given relevant interventions (e.g. glasses, hearing aids);
- receive educational, early intervention and support services;
- receive health and developmental assessment; and
- be followed up by community workers to monitor their response and needs over time.

TABLE 4. COMMUNITY-BASED MONITORING OF HEARING AND VISION IN CHILDREN WITH OR AT RISK FOR CZVS


Age	Vision	Hearing
2–4 weeks	<ul style="list-style-type: none"> Does the infant blink when a bright light is flashed in his or her eyes? Does the infant turn to a diffuse light, such as from a window? (by 6 weeks) 	<ul style="list-style-type: none"> Should show some sign of hearing sounds, e.g. open eyes, blink, look alert If available, an objective hearing screen (e.g. auditory brainstem response or otoacoustic emissions test) should be performed, if this was not done at birth.
3 months	<ul style="list-style-type: none"> A formal eye check by an eye specialist should be performed if possible. Ask families and caregivers whether they have any concern about their child’s vision. Look for any abnormal eye movements or alignment. <p>Check:</p> <ul style="list-style-type: none"> Does the infant look at your face when 10–20 cm away? Does the infant respond to silent smiles or eyebrow raising? Does the infant fix on and follow a dangling ball or toy? 	
6 months	<ul style="list-style-type: none"> Ask families and caregivers whether they have any concern about their child’s vision. Look for any abnormal eye movements or alignment. 	<ul style="list-style-type: none"> Infant should respond by trying to see where a sound is coming from by turning his or her head or eyes in the direction of the sound.
9 months	<p>Check:</p> <p>By 4 months:</p> <ul style="list-style-type: none"> Does the infant watch an adult at 1.5 m? 	<ul style="list-style-type: none"> Infants are listening to loud and very soft sounds and making many different sounds themselves. Perform repeat diagnostic hearing screen (automated auditory brainstem response or otoacoustic emissions).
12 months	<ul style="list-style-type: none"> Do the infant’s eyes converge properly (If you move a toy closer and further away; do the eyes focus on the toy and line up properly?) 	<ul style="list-style-type: none"> Child should respond to his or her name and to words.
18 months	<p>By 5 months:</p> <ul style="list-style-type: none"> Does the infant blink in response to a threat? (Any silent, sudden movement close to the face that causes no breeze, e.g. opening your fist very suddenly) 	<ul style="list-style-type: none"> Child should be able to point to familiar things when asked to do so with simple words. The diagnostic hearing screen should be repeated.
24 months	<p>From 1–5 years:</p> <ul style="list-style-type: none"> Ask families and caregivers whether they have any concern about their child’s vision. Look for any abnormal eye movements or alignment. <p>Check:</p> <ul style="list-style-type: none"> Children should show interest in colourful and interesting objects around them. They should respond to silent smiles, eyebrow raising and winking. They should be able to see objects in their peripheral visual field. They should be able to identify objects of different sizes with each eye while the other is covered. 	<ul style="list-style-type: none"> Ask the parents whether the child appears to hear normally even when spoken to very softly; assess whether the child has appropriate language development (e.g. starting to put words together and a single word vocabulary of > 10 words at a minimum).

Routine health care (10, 11)


Recognizing and responding to warning signs requiring urgent medical care

Community workers should be able to identify and initiate appropriate action when children with CZVS are acutely unwell. They should recognize and respond to danger signs, such as when a child:

- is unable to breastfeed or stops feeding well, or an older child stops drinking or feeding well;
- has convulsions or fits,
- has difficult or fast breathing,
- feels hot or unusually cold or
- presents with persistent or severe irritability.

The community worker should initiate management and/or refer a child with danger signs to an appropriate health facility for urgent assessment and management,  according to local protocols (e.g. integrated management of childhood illness). They should also teach families to recognize the danger signs and to take their child urgently for care to the health facility.

If families and caregivers are concerned about a change in their child's behaviour, even without danger signs, the community worker should listen to their concerns and initiate further assessment and management as indicated. This is especially important for children who have disabilities, who may not be able communicate pain and distress in the same way as other children of the same age. Families and caregivers are usually best placed to recognize changes in the behaviour of their child.

Refer children who present with irritability for assessment of the contributing factors, including to a health facility.  Irritability in children with CZVS may have a number of medical causes.

Prevent illness (10)

Illness can affect children's growth and development. Children with CZVS are susceptible to the same childhood illnesses as other children, but, unfortunately, due to stigma, they may experience barriers to accessing routine health care. The goal of the community worker is not just to treat illness but to help prevent it. Community workers can counsel families and caregivers on four common practices that help prevent childhood illness:

- **Breastfeed the child:** Breastfeeding can prevent illness in infants and children. Use standard recommended infant and young child feeding guidelines (13).
- **Vaccinate the child:** Vaccines protect children from many illnesses. Children with or at risk for CZVS should be given the same vaccines as other children.
- **Wash hands:** Many illnesses pass from person to person through unclean hands. Advise families on simple measures to reduce the risk for infection, including hand-washing, during routine visits.
- **Use an insecticide-treated bed net:** In areas where malaria is common, children under five years (and pregnant women) are at particular risk for malaria, including children who have CZVS. Without the protection of bed nets, children can get malaria repeatedly, which can further harm their health and development. Advise families and caregivers to use bed nets for their young children.

Prevent injury

Community workers should discuss injury prevention strategies with families and caregivers during routine visits. The developmental stage and abilities of each child should be taken into account to reduce the risk for injury.


Recognize and respond to child abuse and neglect (22)

All children need and have the right to a safe, secure environment as they grow and develop. Child abuse and neglect occur in all communities, but children with a disability or chronic illness, including children with CZVS, are more vulnerable. Child abuse can include physical, emotional or psychological abuse, sexual assault and neglect, including medical neglect and abandonment.

Community workers should be able to recognize the signs and symptoms of possible abuse and neglect and support vulnerable children and their families; access to support in the community can help protect children from neglect and abuse. They should know how to respond in accordance with local child protection legislation and services.

When to refer children for further assessment and support

When monitoring of child development identifies children at increased risk for developmental difficulties or there is concern about the child's broader health, vision, hearing or head growth, the concerns should be discussed with the child's parent or primary caregiver, and the child should be referred for further assessment for any additional developmental support they may require. This usually involves referral to specialist service providers or workers who have received additional training in assessing children's development, depending on local resources. It may include referral to facility-level health care, speech and language therapists, occupational therapists or physiotherapists. A comprehensive developmental assessment is required to establish a diagnosis, understand a child's level of functioning and plan additional developmental support.

It is important to recognize the stress that such news can induce in a family and use supportive communication and the general principles of mental health and psychosocial support. (See Module 3.) 

KEY MESSAGES

Rationale for community follow-up

- *Children with or at risk for CZVS are at risk for a broad range of complications that may affect their health, development, hearing and vision.*
- *Close monitoring by community workers can ensure that difficulties are identified early and children and their families are given additional support.*
- *Community workers have an important role to play in coordination and provision of follow-up care for children with or at risk for CZVS by working in partnership with families, facilitating communication among service providers and advocating for affected children and their families in the broader community.*

Community-based monitoring, early identification and management of health complications

Children with CZVS are at increased risk for a number of health problems. At follow-up visits, community workers should:

- measure head circumference, length and weight and interpret measures against the WHO child growth standard;
- monitor and address common complications, such as feeding difficulties, seizures, irritability and drooling; and
- provide routine health care, including checking for danger signs and preventing and responding to acute illness.

Community-based monitoring of development, hearing and vision

Developmental monitoring by community workers involves:

- regular review of the child and family to monitor the child's developmental functioning in all areas (i.e. cognition, language, social-emotional and motor development);
- using structured, locally adapted, validated screening tools, where available, or a broad monitoring approach based on understanding of typical developmental and problems that trigger referral; and
- monitoring hearing and vision.


Referral for further assessment and support

Children who are found to have health problems, are at increased risk for developmental delay or have hearing or vision problems should be referred for:

- further assessment of hearing, vision, health and investigation for CZVS; and
- a comprehensive developmental assessment, including cognitive, language, motor and socio-emotional development, by a health care professional with appropriate training.

Developmental support


Developmental support by community workers includes:

- promotion of healthy development for every child (e.g. through UNICEF/WHO Care for child development, parent or caregiver support groups or local, evidence-based child development programmes);
- additional support for children with hearing, vision and health problems; and
- adapted strategies to promote child development and additional targeted interventions for those with developmental difficulties. (See section 1.3.) 



Promoting and supporting the development of children with or at risk for congenital Zika virus syndrome

LEARNING OBJECTIVES

- ➔ *To understand community-based interventions that can be used to support every child's development.*
- ➔ *To consider how these strategies may be adapted for children with developmental difficulties and/or disabilities.*
- ➔ *To understand the role of community workers in providing targeted support for children with developmental difficulties as a result of CZVS including; language and communication, motor development, everyday activities, socio-emotional development.*
- ➔ *To be able to recognize when to refer,  how to link families with broader support services and the role of community workers in coordinated follow-up of children with/at risk of CZVS.*

Strategies to promote every child's development (10)

To support each child in reaching his or her best potential:

- recognize that all children need and have the right to nurturing care and learning opportunities (23);
- appreciate that each child is unique, with individual strengths and challenges;
- focus on what each child can do as well as the challenges they experience;
- build from where the child is now, noting priorities for the child in his or her family context;
- encourage and make the most of everyday opportunities to play and learn and to go to school;
- consider how a child's developmental difficulties or disability affect how they play, communicate, learn and explore;
- provide extra support for children with disabilities to do these things;
- work with families and caregivers, who are often expert in understanding the needs of their children;
- monitor progress, as the needs of children change over time; and
- support families in providing a safe, nurturing environment for their children, who should have consistent loving attention and a safe environment as they learn.

Community workers can increase parents' and caregivers' knowledge, attitudes and practices in every child's development. Interventions that promote caregiver sensitivity and responsiveness benefit the development of young children, which is sustained into adolescence and adult life (24).

Community workers should make themselves familiar and engage with any local parenting programmes. Such programmes promote parent-child interactions to improve

responsiveness in infants and young children, increase attachment, encourage learning and play and also positive discipline and problem-solving in children's development and care. When such programmes are not available, every child's development should be supported by strategies to promote caregiver sensitivity and responsiveness (25):

- Observe the interaction between children and their caregivers.
- Determine how the caregiver plays and communicates with his or her child.
- Praise caregivers, and point out good things that they are doing for their children.
- Advise and coach caregivers in playing and communicating with their children at home. Identify age-appropriate games and communication activities, and give them an opportunity to practice and receive feedback.
- Ask caregivers about any difficulties they have in playing and communicating with the child at home, and help them to solve the problems (Box 5).
- Ensure that the caregiver has understood, and elicit any questions.
- Plan a review, and agree and record the time and place for the next visit.

BOX 5.

PLAY AND CHILD DEVELOPMENT

Children learn and explore the world around them by playing. Play is important for every aspect of a child's development: thinking, learning, communicating, interacting with others and emotional wellbeing.

Everyday objects and activities can be turned into play. Every child has a right to play. Play involves every sense; therefore, children with developmental difficulties may require extra encouragement.

The UNICEF/WHO Care for child development (25) is a well-known, widely used package, which was developed to promote child development at community level in low- and middle-income settings.

Children with CZVS should be helped to access the same services and care as other children. As children with developmental difficulties or disabilities experience and interact with their environment differently from children without disabilities, standard approaches should be adapted to make them more accessible, according to the individual child's needs.


Additional developmental support for children with developmental difficulties or disabilities as a result of CZVS (26)

Depending on their strengths and difficulties, children with CZVS will have a broad range of additional needs and require additional developmental support. The aim of such support (sometimes called "early intervention") is to improve the child's participation in family and community life and to reduce secondary health and developmental problems when possible. This may include interventions directly with the child, their families and caregivers or their broader caregiving environment. The type of intervention will depend on the child's needs and the family and community environment and will change over time.

Language and communication (26, 27)

Communication involves understanding what others say to us as well as expressing our thoughts, needs and feelings to others. It is important for participation in family and community life, for expressing needs and wants and for broader development (e.g. learning, socio-emotional development).

When language delay or communication difficulties are identified, the child should be referred for further assessment

of health,  including hearing assessment, speech and language therapy and other interventions (e.g. hearing aids), and a comprehensive developmental assessment to identify contributing factors and associated conditions and to prepare an individual early intervention plan. When referral is not possible, a number of resources can be used by community workers to support intervention planning for a child. (See Links to relevant resources at the end of the module.)

Encourage parents to make the most of everyday opportunities to strengthen communication with their child (27, 28), by:

- identifying and responding to the ways in which their child communicates (e.g. facial expressions, gestures, sounds, words);
- making sure they get their child's attention before talking to him or her;
- talking to their child often, during everyday activities, about everyday things; and
- continuing to try and adjust different strategies.


Considerations in planning interventions for children with identified language and communication difficulties, include strategies to:


- address modifiable contributing factors (e.g. hearing aids, if appropriate);
- encourage development of language and communication according to the child's ability and difficulties, building on current skills;
- optimize functional communication (e.g. through gestures, signs, communication aids and assistive devices) where appropriate; and
- optimize and support development in other domains (e.g. thinking and learning, language and communication, social development, everyday activities).

Motor development (26)

Motor development refers to the way in which a child learns to move and use his or her arms, legs, trunk, head and neck (i.e. gross motor development), hands and fingers (i.e. fine motor development) and mouth, tongue and swallowing (i.e. oromotor development). Difficulties in motor development can affect children's ability to explore, play and interact with others.

When concerns about a child's motor development are identified, he or she should be referred for further assessment,

 including health, comprehensive developmental assessment and allied health review, especially physiotherapy and sometimes occupational therapy if possible. (See section 1.2.)

 **1.2** When this is not possible, a number of resources are available for use by community workers to plan interventions for an individual child. (See Links to relevant resources.)

Important considerations in planning early intervention for children with identified motor difficulties include strategies to:


- address modifiable contributing factors when possible (e.g. poor nutrition, seizures, visual impairment modifiable with glasses); and
- promote motor skills according to the child's ability and difficulties, building on current skills.



This may include:

- exercises to promote motor development (e.g. physiotherapy);
- strategies to optimize positioning for carrying, sitting and standing;
- mobility aides and assistive devices;
- prevention of contractures (i.e. fixed shortening of muscles);
- prevention of pressure sores;
- muscle tone management;

- referral to a specialist to monitor hip disease;
- optimize functional mobility;
- prevent secondary complications of motor difficulties; and
- optimize and support development in other domains (e.g. thinking and learning, language and communication, social development, everyday activities).

Everyday activities (26–28)

Every family has its own routines, which are part of everyday life, such as carrying and positioning, feeding (see section 1.2),  **1.2** getting around the community, bathing, face-cleaning, brushing teeth (and managing drooling), dressing, toileting and sleeping. Everyday activities provide an opportunity for children to learn new skills, social interaction and participation in everyday family and community life. In families with children with CZVS, however, various aspects of everyday activities and care may be challenging, and families may require additional support to manage them.

Community workers can help to ensure that families and caregivers receive additional support in the everyday care of their child. An individual child may be referred to a health professional,  such as an occupational, speech or physiotherapist, when available. Where these services are not available, community workers can use a number of resources to support them in providing care and support to families. (See Links to relevant resources at the end of the module and Module 3.)  **3**

Positioning, carrying and getting around the community (27, 28)


Inform and support parents in understanding the importance of positioning their child. Good positioning and carrying are important:

- to help children to communicate, move, play, be comfortable and participate in family and community life;
- for their health, as proper positioning and changing a child's position regularly ensure safe feeding and reduce the risks for pressure areas, joint deformities and contractures; and
- for caregivers, to reduce the risk for low back pain.

Become familiar with and support parents in understanding the principles of good positioning when a child is:

- lying on the side,
- lying on the stomach,
- sitting with a caregiver,
- sitting supported in a chair or pushchair,
- being carried,
- being picked up,
- sitting on the floor or
- standing.

Although lying on the back can be good for resting and sleeping, children should spend less and less time on their backs when awake as they get older.

When available, children should be referred for fitting of mobility and assistive devices,  if necessary to support good positioning and maximize mobility, with adjustment over time.




Social and emotional development



All children learn through play and interactions with other children; however, children with developmental difficulties or disabilities risk being excluded from everyday activities. This has negative consequences for learning, social and emotional development. Community workers should support families in coping with stigma and helping children with developmental difficulties or disabilities due to CZVS to participate in family and community life.

Community workers should encourage families to think about and get ready early for their child to go to school (**Box 6**).

BOX 6. GETTING READY FOR SCHOOL

- Every child has the right to education, and going to school is important for every child's health, development, wellbeing and long-term opportunities.
- Children with developmental difficulties or disabilities as a result of CZVS may experience barriers to going to school. Community workers should educate families and caregivers about the right of every child to education and link families and caregivers with providers in the local education system early, so that the parents can find out about local school options and start getting ready for their child to go to school, including accessing additional support services where appropriate.
- For children below school age, community workers should encourage other peer-group activities, including informal activities and access to formal pre-school services if available.

Having a child with additional health and developmental needs affects the whole family, including siblings. While community workers might not be directly responsible for providing care to siblings, it is important to recognize their needs and to enquire how they are adapting over time. Engage brothers and sisters in interactions at routine visits, when possible and appropriate. Positive sibling relationships and modeling are important for the social and emotional development of all the children in a family. If there is concern about sibling relationships or the wellbeing of other children in the family, the family should be linked with broader psychosocial support, including referral for further assessment and management as necessary.  (See Module 3.)  

- can identify the support required to facilitate access to services (e.g. transport, finances, referral letter) and provide support;
- encourage families to advocate for their child’s needs with referral services (e.g. expressing concerns, asking questions); and
- be aware of and be able to refer families to broader support (e.g. peer support, local community groups). (See Module 2.)  

Recognizing when referral is necessary

It is important that community workers:

- are aware of the available health, education and other services in their community for children with additional needs as a result of CZVS;
- can provide information about referral services to families and obtain consent for referral;

Follow-up

Community workers should monitor each child’s wellbeing, response to interventions and changing needs over time. They may also be well placed to identify the changing needs of the family. Community workers should follow up referrals by maintaining contact with the family and the referral service to review continuing care needs in the community.

KEY MESSAGES

- ➔ *Community workers should promote every child’s development by engagement and strategies to support the sensitivity and responsiveness of parents and caregivers to their child (e.g. through WHO/UNICEF Care for child development or local parenting programmes).*
- ➔ *Children with CZVS should have access to the same services and care as other children. Child development interventions should be adapted to be become more accessible, according to the individual child’s needs.*

- ➔ *Additional support for children with developmental difficulties or disabilities due to CZVS can improve a child's health, development, wellbeing, inclusion and participation. The model for providing early intervention that is appropriate depends on the setting.*
- ➔ *Developmental support for children with CZVS should include:*
 - *language and communication,*
 - *motor development and functional mobility,*
 - *everyday activities,*
 - *socio-emotional development and*
 - *preparing for school.*
- ➔ *Where available, community workers should refer children with developmental difficulties or disabilities due to CZVS to multi-disciplinary health and allied health services for early intervention. 🏠*
- ➔ *Community workers should also refer children with CZVS and their families to additional services and support (e.g. social and community supports). 🏠*
- ➔ *Community workers should monitor their response to interventions and their needs, as children and their families change over time.*

LINKS TO RELEVANT RESOURCES

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of ZIKV. Interim guidance for health care providers: (<http://www.who.int/csr/resources/publications/zika/psychosocial-support/en/>).

Training curriculum for community health workers (http://hcvcommunityhealthworker.org/sites/default/files/sitefiles/CHWT_ParticipantManual_Final.pdf).

mhGAP intervention guide version 2.0 (http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/).

Infant feeding in areas of Zika virus transmission. Geneva: World Health Organization; 2016:
http://apps.who.int/iris/bitstream/10665/204473/1/WHO_ZIKV_MOC_16.5_eng.pdf

Global strategy for infant and young child feeding. Geneva: UNICEF; 2003

(www.who.int/maternal_child_adolescent/documents/9241562218/en/)

Caring for the child's healthy growth and development. Caring for newborns and children in the community. A training course for community health workers. Participants' manual. Geneva: UNICEF, World Health Organization; 2015:

(http://apps.who.int/iris/bitstream/10665/204356/1/9789241504997_ParticipantsManual_eng.pdf?ua=1).

Child development. Geneva: World Health Organization; 2017: http://www.who.int/topics/child_development/en/.

Fernald LCH, Kariger P, Engle P, Raikes A. Examining early child development in low-income countries: a toolkit for the assessment of children in the first five years of life. Washington DC: World Bank; 2009: <http://siteresources.worldbank.org/EXTAFRRREGTOPEDUCATION/Resources/444707-1291071725351/ExaminingECDtoolkitFULL.pdf>.

Newborn and infant hearing screening: current issues and principles for action. Geneva: World Health Organization; 2010: www.who.int/blindness/publications/Newborn_and_Infant_Hearing_Screening_Report.pdf.

Primary ear and hearing care: training resource. Geneva: World Health Organization; 2006:

http://www.who.int/pbd/deafness/activities/hearing_care/en/.

Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low- and middle-income countries. A review. Geneva: World Health Organization; 2012:

http://apps.who.int/iris/bitstream/10665/97942/1/9789241503549_eng.pdf

Early child development and disability: a discussion paper. Geneva: World Health Organization, UNICEF; 2012:

http://apps.who.int/iris/bitstream/10665/75355/1/9789241504065_eng.pdf?ua=1.

Child injuries and violence prevention. Geneva: World Health Organization: [who.int/violence_injury_prevention/child/en/](http://www.who.int/violence_injury_prevention/child/en/)

mhGAP Humanitarian Intervention Guide (mhGAP-HIG): Clinical management of mental, neurological and substance use conditions in humanitarian emergencies. Geneva: World Health Organization and United Nations High Commissioner for Refugees: http://apps.who.int/iris/bitstream/10665/162960/1/9789241548922_eng.pdf?ua=1

UNICEF Care for child development package: www.unicef.org/earlychildhood/index_68195.html

Developmental support for children with developmental difficulties or disabilities. Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low- and middle-income countries. A review:

http://apps.who.int/iris/bitstream/10665/97942/1/9789241503549_eng.pdf

WHO. Early child development and disability: a discussion paper:

http://apps.who.int/iris/bitstream/10665/75355/1/9789241504065_eng.pdf?ua=1

United Nations Convention on the Rights of the Child: <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

United Nations Convention on the Rights of Persons with Disabilities:

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

UNICEF: The State of the world's children 2013: children with disabilities: www.unicef.org/sowc2013/.

WHO. Training in the community for people with disabilities (1989):

<http://www.who.int/disabilities/publications/cbr/training/en/>

WHO. Promoting the development of young children with cerebral palsy:

http://apps.who.int/iris/bitstream/10665/62696/1/WHO_RHB_93.1.pdf

WHO. Community-based rehabilitation (CBR): <http://www.who.int/disabilities/cbr/en/>

MODULE 2

Psychosocial support for caregivers and families of children affected by congenital Zika virus syndrome

This module provides guidance for delivering mental health and psychosocial support to caregivers and families affected by complications associated with ZIKV, with emphasis on CZVS. The techniques can be used by community workers in the home and the community.

- 2.1 Common reactions and assessment of mental health and psychosocial needs*
- 2.2 Providing psychosocial support and facilitating a peer support group*
- 2.3 Management of severe conditions*



Common reactions and assessment of mental health and psychosocial needs

The effect of complications associated with ZIKV on the families and caregivers of affected children can be substantial (29). The challenges of life-long caregiving may be associated with physical and psychological problems. Community workers can assess how caregivers respond to the challenges they experience, provide strategies to improve coping and identify individuals with symptoms of psychological distress who should be referred for additional support from mental health specialists.

Common reactions

People react in various ways to being affected by ZIKV and its potential consequences. It is normal for families and caregivers and close family members to experience short-term emotional distress as part of a normal reaction to an unusual situation.

Mothers who have become infected with ZIKV during pregnancy or caregivers who are told that their child may have or has microcephaly may be more likely to develop symptoms of distress, such as:



- irritability, anger (feeling unsupported, anger at the injustice, why me?);
- guilt, shame (blaming themselves for their infant's condition, for being helpless or needing others);
- insomnia or nightmares;
- physical symptoms (shaking, headaches, feeling very tired, loss of appetite, aches and pains) with no organic cause;
- excessive worry, anxiety, fear (uncertainty, fear of the unknown and the effect it will have on the family);
- crying, sadness, very low mood; and
- grief, which is a normal response to any major loss, including the loss of a family member's health or well-being. Grief has both mental and physical effects. People grieve in different ways, and there is no right or wrong way to grieve.

Some of the above-mentioned psychological reactions are also common and normal during pregnancy, such as feeling very tired or having sleeping problems. In women with psychological distress, physical symptoms such as headaches may worsen.

The bond or attachment that mothers develop with their infants might be threatened by ZIKV. Mothers may feel detached or resentful towards their child, during pregnancy or in the early stages of the child's life.

Most people recover from these emotional reactions to a stressful life event spontaneously, but they can progress to severe mental health problems.

Community workers should be able to identify more severe conditions in order to support the affected individuals to access appropriate support for their own wellbeing and that of their families. The presence of some symptoms may reflect a psychological reaction or mental health problem that requires a detailed assessment and intervention by a specialist (4).

- Psychological symptoms and reactions are considered severe if a person cannot function in his or her daily life due to distress for more than 2 weeks. This might include caring for themselves or their children, or they may be a danger to themselves or their children. If potential abuse or neglect of a child is identified, community workers should refer to child protection and mental health specialists. 
- All illnesses that are associated with pain, physical disability, neurodevelopmental impairment and distress increase the risk of suicide. Community workers should identify possible thoughts or plans of suicide and self-harm and be able to refer the person to a health care professional immediately. 
- People commonly use alcohol or drugs to cope with stress, which can have serious health and social consequences for the individual and families.

The partner or close family members may react similarly to the stress of the situation and to the uncertainty of how it will affect the child and the family. Relationships with intimate partners and the family may be compromised as people cope with the new challenges associated with CZVS. Families and caregivers are nevertheless important sources of care and support for mothers during and after a diagnosis of ZIKV and any complications for the child and family.

Various socio-economic problems might arise from the complications associated with ZIKV (30).

- Social isolation and disruption of social networks may result if people are abandoned or strongly stigmatized.
- Access to basic or specialized education and health care for children and mothers may be compromised.
- There may be increased financial strain as parents find it difficult to return to work and provide for the increased needs of their child.

Assessment of mental health and psychosocial needs

A general principle of assessment is to ask supportive, non-judgemental questions to determine the presenting problem of the caregiver and his or her own understanding of the problem (Box 7).

BOX 7. QUESTIONS FOR ASSESSING MENTAL HEALTH AND PSYCHOSOCIAL PROBLEMS IN FAMILIES AND CAREGIVERS

Current stressors

- What is your greatest worry these days? What are your most serious problems right now? How severe are those problems?
- How are these problems or worries affecting you?

Coping strategies

- How do you deal with this worry or problems every day?
- What are some things that give you comfort, strength and energy?
- What activities do you enjoy?

Social support

- With whom do you feel most comfortable in sharing your problems?
- When you are facing difficulties, who do you turn to for help or advice?
- How is your relationship with your family?
- In what way do your family and friends support you?

Duration and severity of symptoms

- For how long have you felt sad or worried?
- To what extent do these stressors affect your daily life, such as relationships with family and friends and effects on your job or studies?


General health history

- Have you had any serious health problems in the past?
- Do you have any health problem for which you are currently receiving care?

Mood and sadness

Identify the common complaints of people who are experiencing low mood or sadness (moderate-to-severe depressive disorder):

- body aches and pains;
- low energy, feeling tired, problems with appetite and sleep;
- feeling sad or irritable or feeling excessive worry that won't go away;
- loss of interest or enjoyment in activities they used to enjoy.

If the person has difficulty in doing his or her usual work, at school or domestic or social activities and the difficulties persist for 2 weeks, refer the person to a health or mental health professional. 

Alcohol or drug use

Identify common difficulties with alcohol or drug use which may be present if a person is:


- has difficulty in carrying out usual work, school, domestic or social activities;
- is vomiting, shaking, has slurred speech, injection marks or lack of self-care; or
- is using other people's prescription drugs or trying to get such drugs for a non-medical reason.

Explore possible difficulties with alcohol or drug use by explaining to the person that the following questions are part of the routine assessment, and ask the questions in a non-judgmental, culturally sensitive way. For example, say, "I need to ask you a few routine questions as part of the assessment. Do you drink alcohol? [If yes] How much per day each week?" "Do you take any tablets when you feel stressed, upset, afraid or are in pain? Do you take sleeping tablets? [If yes] How many do you take per day each week? Since when?"

Self-harm and suicide

Identify possible thoughts of self-harm and suicide, including:

- current thoughts, plans or acts of self-harm or suicide;
- history of thoughts, plans or acts of self-harm or suicide;
- signs of self-injury: cuts, wounds, signs of poisoning, loss of consciousness;
- severe emotional distress: hopelessness, violence, extreme agitation, social isolation.

If you suspect that someone is at risk of self-harm or suicide, refer him or her to a mental health professional immediately. 

- If a person who has self-harmed must wait for treatment, **do not leave him or her alone.**
- Remove any means of self-harm.

Asking about self-harm does not provoke acts of self-harm, and asking about suicide will not give a person the idea of committing suicide. Questions about suicide may be perceived as offensive, but they are essential in all assessments.



Providing psychosocial interventions and facilitating a peer support group

*This section describes a variety of interventions for changing behaviour and supporting people who are reacting to stressors. These interventions can be delivered in communities by community workers and help to enhance coping, promote resilience and empower families and caregivers of children with CZVS to adjust to their diverse and changing needs. Practical tips are listed in **Box 8**.*

The interventions described in this section can be used in combination and with the care and support described in Module 1.

➡ 1 *Community workers are encouraged to consult a mental health professional for families and caregivers who are experiencing more severe distress.*

LEARNING OBJECTIVES


- ➔ *Be able to provide effective psychosocial interventions for people affected by complications associated with ZIKV.*
- ➔ *Inform people affected by ZIKV, their families and caregivers about expected complications while maintaining hope and encouragement.*
- ➔ *Link families and caregivers to community resources and multidisciplinary care, depending on the resources available.*

BOX 8. PRACTICAL TIPS FOR COMMUNITY WORKERS DELIVERING PSYCHOSOCIAL INTERVENTIONS (31,32)

- Support safe access to the services necessary for survival and for living in a dignified way, such as:
 - social or protection services (countering violence, positive parenting, interventions for special needs);
 - shelter, food aid, water and sanitation (housing interventions);
 - community centres or hubs, self-help and support groups (positive parenting, rehabilitation and addiction treatment);
 - income-generating and other vocational activities; and
 - education services (formal and informal).
- Help families to find more ways for their child to play by accessing child-friendly spaces or other structured activities for children and adolescents.
- Ensure physical health by supporting regular health assessments, vaccinations and access to assistive devices.
- Provide advice about basic self-care (e.g. nutrition, physical activity, safe sex, family planning).
- Ensure care by another family member or other suitable person who can take over the care duties temporarily while the main caregiver takes a rest or does other important activities. Help the person to identify supportive, trusted family members, friends and community members and to consider how each could be involved.
- When making a referral, help the person to access the referral place (e.g. provide directions to the location, operating hours, telephone number, or join them for the first appointment).

INTERVENTION A.

Supportive communication

Tailor communication for each person and his or her needs. (See section 1.1).  Be aware of cultural differences and also of your own cultural background and beliefs in order to set aside any biases. Offer help in the most appropriate way for the people being supported.

A person's spiritual or religious beliefs may be very important in helping them through pain and suffering, providing meaning, and giving a sense of hope. Being able to pray and practice rituals can be a great comfort. A person's faith might also affect their decisions about health care if they are experiencing complications associated with ZIKV. A crisis – particularly with a terrible loss – may cause people to question their beliefs. Learning that a child has CZVS may feel like a loss. People's faith may be challenged, made stronger or changed by this experience.

- Be aware of and respect people's spiritual or religious beliefs.
- Ask the person what generally helps them to feel better. Encourage them to do things that help them to cope, including spiritual routines if they mention them. Listen respectfully and without judgement to spiritual beliefs or questions the person may have.
- Don't impose your own beliefs or spiritual or religious interpretations of the crisis.
- Don't agree with or reject a spiritual belief or interpretation of the crisis, even if the person asks you to do so.

INTERVENTION B.

Identify and respond to immediate needs and concerns (33)

People faced with the news of a disease outbreak, such as ZIKV, or complications for their child or family will often need:

- a feeling of safety and protection;
- information about the prognosis, the effects on their loved ones and available services;
- someone who is willing to listen;
- to be able to contact their loved ones;
- specific support from their culture or religion; and
- to be consulted and involved in decisions that affect them or their child.

To assist them, community workers require:

- accurate information about ZIKV;
- information about the people affected by complications associated with ZIKV;
- practical support (e.g. advice on prevention, mosquito nets); and
- to know who else is helping locally and what kind of support they are providing.

Responding to needs

Prepare before approaching families, by learning about:

- transmission: what happened, when they learnt the diagnosis, what the symptoms were, how many other people in the area are affected and who are they;
- the available services and support: who is providing services for basic needs, where and how people can access services and support; and
- safety and security: ZIKV is still transmissible; what are the dangers in the environment, what areas or activities should be avoided?

Look:

- for the safety of individuals and families;
- for obvious, urgent basic needs like food, shelter and health care; and
- serious distress reactions.

Listen:

- contact people who may need support,
- ask people about their needs and concerns and
- help people to feel calm.

Link:

- help people to fulfill their basic needs and access services in the community,
- help people to cope with their problems,
- give information and
- link people with their loved ones and social support.

INTERVENTION C.

Link to individual and family social support (29)

People tend to cope better when they have friends, family members or community groups that offer care and support. If the mother of a child with CZVS has a partner, it is helpful to include that person in discussions to encourage and support each other.

Community workers should recognize that emotional distress can affect a person's ability to accept support when they need it. Start by asking questions about the supportive people in their lives: "Who might you could go to if you needed help or advice?", "Who do you trust enough to talk about some of your worries?" Ask the person if she or he would feel comfortable talking to one of those people. Sometimes, just spending time with others can help a person to cope, even if they aren't talking about their problems. Try to encourage the person to spend time with people they trust, perhaps engaging in activities that they both enjoy.

Partners, siblings and other family members may be worried and feel uncomfortable or even frightened by having a family member with CZVS. Some may not want to "interfere" by supporting them. Community workers can suggest or directly help a family to designate clear roles for each member in providing care and support and encourage inclusion and strengthening of the family unit to face the challenge. Family meetings can be used to address concerns and the ways in which each member can provide support, to talk, discuss CZVS, make long-term plans for the disabled family member, share information and emotions and make practical plans for daily needs or short respites for the caregiver. Families can be referred to peer support groups.

INTERVENTION D.

Link to community resources and services

People affected by the complications associated with ZIKV risk becoming isolated from people and resources in their communities. People who are distressed should be kept engaged and active to prevent isolation. Support should be embedded in and linked to existing resources and services in the community.

Community workers are well placed to help people address urgent needs and access local services, including individual counselling, if available. They can help them to find supportive resources, such as places, groups and people in the community, to help them meet their needs.

Table 5 lists services and resources that might be available in the community. Community workers may use this list to start collecting ideas with colleagues and families about who else might be available to provide care and support. Consider how families might make contact with these services and people who could facilitate the links.

Community workers might ask the caregiver or family to identify potential barriers to accessing the services and resources, and assist them in solving problems and overcome barriers. Just identifying barriers might be enough in the early stages, as it may not be possible to find an immediate solution. People may slowly work towards overcoming the problem with the help of others. (See **Intervention G** for problem-solving strategies.)

TABLE 5. SERVICES AND RESOURCES THAT MAY BE AVAILABLE IN THE COMMUNITY

Sector	Examples
Non-specialist and specialist health services and care providers	Primary care workers, nurses, neurologists, psychiatrists, physical therapists, occupational therapists, speech language therapists, paediatricians, psychologists, ophthalmologists, audiologists, community workers, social workers, inpatient or outpatient service providers, outreach care workers
People affected by complications associated with ZIKV	Groups or individuals living with GBS, children living with CZVS, family members and caregivers
Community	Self-help groups, faith-based groups, savings groups, recreational groups, mothers' groups, women's groups, youth groups, cultural groups, helplines
Education and employment	Schools, education, income-generating or vocational training programmes
Nongovernmental organizations	Local and international civil society organizations (e.g. working in health, education, disability rights, legal aid, child protection, disability rights, gender-based violence or psychosocial support)
Government services and benefits	Health, education and justice systems, child welfare, pension, disability, social welfare, transport

Sources: Adapted from IASC Referral Form and Guidance (34) and mhGAP 2.0 (4)

INTERVENTION E.

Discuss stress and positive coping methods (35)

Families and caregivers should understand that stress is a normal response to the challenges they are facing in caring and supporting a child with CZVS and that they are not alone in experiencing the symptoms. The community worker should help them to recognize “early warning signs” of stress and help them strengthen their positive coping methods.

Explain that stress as a common, normal response to difficult situations. At the same time, acknowledge that the parents of children with disabilities experience higher levels of stress than other parents. Tell parents or caregivers that it is normal to have difficult feelings and thoughts. Discuss common physical and emotional symptoms of stress. When people are very stressed for some time, they may experience changes in their:

- **emotions:** sadness, anger, fear, anxiety, guilt;
- **daily difficulties:** forgetfulness, trouble sleeping, difficulty in focusing, lack of energy for usual activities;
- **physical problems:** headaches, pain, illness, upset stomach, changes in appetite;
- **thoughts:** thinking too much, worries, self-blame; and
- **behaviour:** withdrawing from people, misuse of alcohol and other substances.

Emphasize that managing stress is important for caregivers and families, even when time and resources are very limited.

- Caregivers who take care of themselves may have more energy to take care of others.
- When people are less stressed and have more energy, they can remain calm and consistent and are best able to engage with their children for learning and development.

- Although caregivers with limited money or time may find it more difficult to care for themselves, this is important for the entire family. Community workers could ask, “What have you done for yourself lately?” or “What things do you enjoy doing when you have time alone?”
- Families and caregivers must be kind to themselves and set small goals for self-care. Community workers could explain, “Identifying what is important to you in your role as a parent can help guide your actions even when times are difficult.”

Strengthening positive coping methods

Parenting and caring for a child with additional health and developmental needs can be physically and emotionally stressful. Community workers could explain, “Finding ways to manage stress and look after yourself as parents is important to help you and your child.” Or they could ask, “What are you doing to take care of yourself, maintain your wellbeing and manage the stress that can come with caring for a child with developmental difficulties?” They should tell families and caregivers:

- Make your own wellbeing a priority.
- Take care of yourself in the best way you can, by trying to eat well, get enough sleep and take care of your health.
- Do activities that are important to you and that you enjoy. Identify positive ways to relax, such as yoga, meditation, prayer, singing and listening to music.
- Reach out to others and stay connected. Sometimes, families and caregivers may have to identify trusted family members or friends who can support them, by taking care of their children for a short time (i.e. providing respite). See **Intervention C** for ideas for helping families and caregivers engage with supportive people around them.

INTERVENTION F.

Stress management (29)

Several simple relaxation exercises and techniques can help in reducing the symptoms of stress. Community workers can teach caregivers and families techniques such as slow breathing (**Box 9**) and advise them to practice this exercise at home or at work whenever they experience any emotional or physical reaction to stress.

There may be positive stress management techniques specific to the cultural setting of community workers that could be used for relaxation. Explore these with families and caregivers to see what might work for them.

INTERVENTION G.

Discuss problem-solving techniques (36)

People who feel distressed and overwhelmed find it especially difficult to solve everyday problems by themselves. Community workers can use problem-solving techniques to help families and caregivers to address major stressors, such as discrimination or difficulty in accessing services. When stressors cannot be resolved or reduced, problem-solving techniques may be used to find ways to cope emotionally with the stressor.

Identify the problems, and discuss solutions and coping strategies; prioritize them, and discuss how to use the solutions and strategies. In general, do not give direct advice. Try to encourage people to find their own solutions.

Examples of community worker questions for supporting problem solving:

- “Think about a time when feeding your infant went well or when you were able to get your infant to smile. How do you explain your success, what did you do well?”
- “As you think about the strategy for feeding, offer gentle encouragement and talk to your child to let them know what you are doing. Put yourself in the role of your child and imagine it was you. Ask yourself how it feels to be

BOX 9. SLOW BREATHING TECHNIQUE

Explain the goal:

I am going to teach you how to breathe in a way that will help relax your body and your mind. It will take some practice before you feel the full benefits of this technique. When we feel stressed, our breathing becomes fast and shallow, making us feel tense. To relax, you must start by changing your breathing.

Relax the body (demonstrate for and with the person):

Before we start, relax your body. Gently shake and loosen your arms and legs. Let them go floppy and loose. Roll your shoulders back, and gently move your head from side to side.

Practice slow breathing:

- Now, place one hand on your stomach and the other hand on your upper chest. I want you to imagine that you have a balloon in your stomach, and, when you breathe in, you are going to blow the balloon up, so that your stomach will expand. When you breathe out, the air in the balloon will also go out. Remember, we start by breathing out until all the air is out; then breathe in. If you can, try and breathe in through your nose and out through your mouth, that's the best.
- The second step is to slow the rate of your breathing. We are going to take three seconds to breathe in, then two seconds to hold your breath and three seconds to breathe out. I'll count with you. You may close your eyes or keep them open. So, breathe in, 1, 2, 3. Hold, 1, 2. And breathe out, 1, 2, 3. Did you notice how slowly I count? [Repeat this breathing exercise for approximately one minute]

Encourage practice at home:

When you practice on your own, don't be too concerned about keeping to exactly three seconds. Just try your best to slow your breathing when you are stressed.

spoken to calmly, without a raised voice, and to understand what is happening or about to happen."

- "Which of the strategies for feeding you heard about today do you already use, and what have you learnt from your experience that makes these strategies work or not work?"
- "Ask yourself how confident you are that you can manage the situation we just discussed."
- "Congratulate yourself when you feel you've done something well as a caregiver."

Practice in problem-solving allows caregivers to monitor and adjust their behaviour and their goals on the basis of what is working well. It also helps them to identify areas that might require more work, without the help of a community worker or peers in the future. To help parents, community workers could model self-reflection when demonstrating skills to parents (i.e. position or feeding) and ask questions such as those listed above.

TABLE 6. STEPS IN MANAGING PROBLEMS

Step	Description
1. List problems	List the problems the person is experiencing and together choose one to start with.
2. Define	Try not to include more than one problem. Ask the person to describe the issue and how it affects him or her.
3. Discuss	Encourage the person to think of as many solutions to the problem as possible, and encourage the person to come up with ideas, rather than directly giving solutions.
4. Prioritize	From the list of potential solutions, choose those that are most helpful and feasible. Helpful strategies have few disadvantages for the person and others. Help the person to choose the solutions they will try first, if there is more than one.
5. Plan action	Discuss with the person how and when they will use the solution. Discuss what resources (e.g. money, transport, a friend) they might need to carry out the plan.

Adapted from WHO Problem Management Plus (36)

INTERVENTION H.

Thinking and acting healthy (37, 38)

The aim of this strategy is to improve mood by identifying what is important to caregivers and their families and encouraging them to engage in activities that they find enjoyable. It is a tailored approach to helping people improve their mood with small changes in day-to-day actions and thinking more positively.

The intervention is adapted from the WHO Thinking healthy programme (37), which is a psychological treatment approach for perinatal depression. The approach can be broken down into three steps. Community workers might work with caregivers in a series of meetings.

1. Start by asking the caregiver to identify, “something important to you or your family.”

This might be a personal characteristic, like being a good mother, loyalty, compassion or nurturing the family. It might be a goal, such as being more patient or learning new ways to engage with the child.

2. Discuss activities associated with the important values or goals of the caregiver.

Community workers can use the activity monitoring form below to discuss small changes to everyday activities that the caregiver can make at home that help promote positive thinking and are in line with their values. Caregivers can record their actions each day to work towards their goals. If making such changes is too difficult to do alone, community workers could encourage the caregiver to consider who in their life might give them support and specific ways in which that person could do so.

3. Report back.

Encourage the caregiver to try to add the small changes to his or her routine during the coming week and then to reflect back about the experience. Ask the caregiver also to reflect on the unhealthy behaviour that made the changes more difficult. Ask, “What alternative action could you take that would help you to reach your values and goals?”

Community workers should try to:



- enlist support from families to assist the caregiver in these activities;
- encourage the caregiver to carry out the activities and practice using the daily activity monitoring form;
- help the caregiver to overcome problems in these activities; and
- offer encouragement after each small step the caregiver takes.

INTERVENTION I.

Advocacy and stigma reduction (39)

Concern about ZIKV in pregnant women and/or CZVS may cause social problems for families and communities, such as stigma, discrimination, abandonment and financial strain. These problems also affect people’s capacity to access care and other support services.

Community workers can help to reduce stigmatization of people affected by ZIKV, using the following strategies to help promote inclusion:

- Do not talk about individuals affected by ZIKV in a negative way, and discourage others from doing so.
- Talk openly in the community about the effects of ZIKV, and provide accurate information about people affected by mental health problems.
- Form partnerships with community and religious leaders, local administrative staff, teachers, the criminal justice system and traditional healers. When trust with these people and services is built, they will be more likely to listen to messages about ZIKV.
- Help those affected by ZIKV to tell their stories (39). See also Module 3 of the Manual for public health planners and managers.  

ACTIVITY MONITORING FORM

Time of day		Behaviour or action	Daily monitoring						
			1	2	3	4	5	6	7
	Early morning								
	Late morning								
	Midday								
	Afternoon								
	Evening								
	Night								

Source: Adapted from WHO Thinking healthy programme (37)

- Refer to WHO training for caregivers of children with developmental disorders or delay on the WHO website, which covers advice for community workers in discussing myths with caregivers (35).
- Use social media to spread messages about inclusion of people affected by complications associated with ZIKV, such as websites, social networks, print materials and radio.

Facilitation of peer support groups (40–44)

Peer support groups can be excellent sources of support, awareness-raising and advocacy for complications associated with ZIKV. By connecting the families and caregivers of children affected by CZVS, such groups can promote large changes within the community and be a strong resource for people involved.

Caregiver support interventions are designed to educate parents about the disability, related issues such as sleep problems and the interventions and services that may be available to them. Such support can be accessed through self-help, peer support or health services.

Caregiver peer support is commonly organized or facilitated by a community worker, who brings together caregivers of children with a disability to provide:

- opportunities to share information about the resources and services available;
- strategies to assist in the daily care of children; and
- emotional and psychosocial support by providing a platform to discuss stereotyped attitudes of neighbours and friends and traditional myths and misconceptions about the cause of the disability.

Caregivers who care for and raise children with CZVS, especially in rural areas where there may be fewer health and social care services, have unique skills and experience that should be harnessed to address the unmet needs of other children with disabilities and their caregivers.

People faced with a stressful experience use a variety of coping strategies. Adapting to or managing significant stress is known as “resilience.” Caregivers of children with CZVS are resilient and may be able to offer coping strategies to other caregivers. Sharing their experiences and offering to support each other empowers families to move from being receivers of care to active contributors.

Peer support can be delivered in person, by telephone or online, in a group or led by peers or a facilitator. Steps in planning and facilitating a peer support group are listed in **boxes 10, 11 and 12.**

Handling challenging situations (46, 47)

Caring for a child with a disability is difficult, and caregivers may become upset when they are tired, are trying everything they can to support their family and are still having a difficult time. Any person in this situation may be angry or stressed and could bring up topics that are confrontational or a question that is difficult to answer. When this happens, the job of the facilitator is to change the direction of the negativity by identifying the problem and addressing it immediately.

- Validate and summarize the parent’s concern. “That’s a really good point. As parents, many of us feel that interacting with our children is difficult, and it sometimes seems there is nothing we can do to improve our relationship with our child.”
- Clarify the problem or question. “When you say you’ve tried everything that we’ve discussed today and it hasn’t worked, what do you mean?”

If the response is not clear, community workers may ask for an example to clarify which part of the discussion the caregiver is referring to. They may be talking about all of the strategies the group has discussed, but they are probably talking about a specific area, for example how responsive the child is during feeding or bathing. This will help to understand the specific problem.

BOX 10. PLANNING A PEER SUPPORT GROUP (45)

1. Contact health services, nongovernmental organizations and other community groups.

- Identify the education, health and disability services or support groups in the community.
- Make personal contact with the services identified, and discuss the provision of resources or linking people to the group.
- Contact community and spiritual leaders to help make the voices of families heard in the community. (Refer to Intervention D for more information on linking to community resources.)

2. Decide who will lead and facilitate the group; this might be a community worker, a caregiver or family member.

3. Book and confirm the meeting place.

4. Decide who will be invited. Consider the type of caregiver who may benefit from peer support, and what personal characteristics or specific needs they might have that would make them good group members. Caregivers of children with the same type of disability or range of disabilities within the same spectrum of mild, moderate or profound might be grouped so that they can more effectively share their experiences and knowledge in helping their children.

5. Find peer caregivers and invite them to the group by:




- placing a flyer or brochure in the local library and other places where caregivers spend time, such as health centres, schools, childcare centres and public transport stops;
- speaking to people in the community about the group to ensure parents and community workers identify you as the peer group leader when they are ready to make contact;
- using appropriate social media to spread the word; and
- by word of mouth once the group starts.

6. Decide what to cover during the session, create a brief agenda, and think about what to bring, such as name tags or an attendance list.

7. Become familiar with and practice using supportive communication and psychosocial interventions strategies, outlined in modules 1 and 2. ➔  


- Explain the meaning of the topic by reflecting on the discussion. “Let’s think back to what we said about responsiveness. Can you (or anyone) remember what we discussed about responsiveness for supporting parent–child interactions during feeding?” Ask the individual or group to recall what was discussed, and clarify the answer if necessary. “Very good, that is correct. We said that parents should use a gentle, calm voice while they are feeding their child. We also discussed what a caregiver should consider doing before starting to feed the child. What did Maria mention about preparation?”
- This might be all that needs to be done if miscommunication is the problem. If not, then continue by acknowledging the parent’s role. “You are the expert on your child and your family, and you know what works and what doesn’t.”
- Ask the person if he or she would be willing to try other strategies. “Do you think you could try these strategies during the next week and remember when things no longer go well? We can then see next week where we can offer more support. Come and chat with me after the meeting so that I can find out the best time to come and see you next week.”
- If the complaint is about a facility, suggest discussing it outside the meeting. Tell the group that specific complaints about a facility are best dealt with directly by the facility.

BOX 11. FACILITATING A PEER SUPPORT GROUP

1. *Start with a breathing technique (see Box 9).*
2. *Ask participants to introduce themselves, and state the “ground rules.” Ask participants why they joined the group and what they expect to gain.*
3. *It is important that they understand that their stories will be kept within the group. People will be more willing to share experiences when they trust that no one outside the group will criticize them. The community worker might say at the beginning, “Everything we say is confidential and will not leave the room.”*
4. *Agree on logistics, including the frequency of meetings – “Should they be held weekly, every two weeks or monthly?” – and their length.*
5. *Generate ideas for invited speakers and topics of interest for the next meetings, such as:*
 - information about developmental delay, congenital abnormalities and the common psychosocial concerns of parents of children with a disability; (See Links to relevant resources and sections 1.4 and 1.5.)   
 - teaching parents to advocate on behalf of their children for resources and funding, such as a community meeting on the needs of the caregiver group; (See **Intervention I**.)
 - stress management (see **Intervention F**).
6. *Legal rights. Peers may provide others with information on legislation and regulation and keep them aware of changes to laws and the rights of their children.*
7. *Close with snacks and socializing, singing a traditional song, a relaxation activity or a phrase, allowing sufficient time for caregivers to share an enjoyable activity.*


- If there is not enough time to discuss an issue, community workers may suggest reviewing it at the end of the session. “Sleep time is a risky time for many parents. Let’s work through this part first and then touch on the rest at the end of our session today.” Or, “We will cover that at our next group meeting. Let’s work through this section and then speak at the end of the meeting if you have a specific concern that you would like to discuss with me before our next group meeting.”
- Ask the group whether it has had experience in dealing with the situation. “Is anyone else having this same problem? Do you have any suggestions for dealing with it?” If unsure of the answer, let the caregiver know. “This is a tricky question, and we don’t have the answer. Maybe we should ask one of the expert educators to help answer it. Where can we find more information on this topic?”

BOX 12. PRACTICAL TIPS FOR COMMUNITY WORKERS IN FACILITATING PEER SUPPORT GROUPS


1. Peers may wish to invite friends to the first meeting, so that they feel supported and have someone to help them commit themselves to attending.
2. Group facilitation is a combination of communication (speaking and active listening) and interpersonal interaction. (See **Intervention A.**)
3. Peers often give advice in a way that is easier for families and caregivers to understand because they speak the same language; this makes it easier to ask for support.
4. Provide psychoeducation by using storytelling to explain concepts such as the developmental potential of children and parental stress. To help the group understand the information, describe a peer caregiver’s experience in successfully supporting their child’s condition or managing stress.
5. Keep caregivers motivated by identifying and checking with them the goals they would like to achieve. Link parents’ concerns with the topics covered during meetings.. If their concern requires more intensive support, link the caregiver with people in the community who can support them.
6. Invite several peers to facilitate the sessions, to support each other in managing group dynamics. Provide feedback after the session on what went well and how to improve the next time.
7. Communication (speaking and active listening) and interpersonal interaction are necessary. Prompt caregivers to discuss topics, and ask appropriate questions to keep the conversation flowing. (See Module 1.) 
8. Take time to reflect and get feedback after each group session on how the group is managed. For example, ask “What did I do well as a group facilitator tonight?” and “What could I do better next time?” This is easier when a second facilitator is involved, so that reflections can be shared.
9. When a person brings up a difficult topic or question, determine what the person is referring to by validating the concern, and then assure them that the problem or question is clear. “Big issues” are often simply misunderstandings.






Management of severe conditions

When severe reactions to stress are seen, the initial intervention should be tailored to the person's needs. When possible, the person should be referred for further evaluation and care. 


LEARNING OBJECTIVES

- ➔ *Be able to assess when someone is in a very low mood or feeling sad, misusing alcohol or other substances, and provide general care and management.*
- ➔ *Be able to identify people at risk of self-harm or suicide.*
- ➔ *Recognize when to refer people for further management. *


General principles for the management of low mood and sadness

- Offer psychosocial support interventions. (See section 2.2.)
 
- Provide basic psychosocial information for the person and the family. Emphasize that:
 - Depression is a very common condition that can occur in anybody, both men and women and at any age.
 - The occurrence of depression does not mean that a person is weak or lazy.
 - The negative attitudes of others (e.g. “You should be stronger”, “Pull yourself together”) may be due to the fact that depression is not a visible condition (unlike a fracture or a wound) and the false idea that people can easily control depression.
- Encourage the person to do as many of the following as possible, even if it is difficult, as they can all help to improve mood (48):
 - Try to start again (or continue) activities that you previously enjoyed.
 - Adhere to regular sleeping and eating habits.
 - Try to be as physically active as possible.
 - Try to spend time with trusted friends and family.
 - Talk to someone you trust about your feelings.
 - Try to participate in community and other social activities as much as possible.
 - Remember that, with the right help, you can get better.
- The person should be aware of thoughts of self-harm or suicide. If they notice these thoughts, they should tell a trusted person and go for help immediately. The community worker should report and refer the person to a mental health professional immediately. 

General principles for the management of substance use


- Engage the person in a discussion about their substance use in a way that he or she is able to talk about both the perceived benefits and the actual or potential harm, taking into consideration what is most important in the person’s life.
- Steer the discussion towards a balanced evaluation of the positive and negative effects of the substance by challenging overstated claims of benefits and raising some of the negative aspects, which are perhaps being understated.
- Avoid arguing with the person, and try to phrase advice in a different way if it meets resistance. Try to understand the real impact of the substance on the person’s life at that time.
- Encourage people to decide for themselves whether they want to change their pattern of substance use, particularly after a balanced discussion of the pros and cons of the current pattern of use.
- If the person is still not ready to stop or reduce their use, ask him or her to come back for further discussion, perhaps with a family member or friend.
- Substance abuse by women who are pregnant or breast-feeding is particularly problematic:
 - Inform women that drug use can interfere with the menstrual cycle, sometimes creating the false impression that they cannot become pregnant.
 - Advise and support women who are pregnant to stop use of all psychoactive drugs. Pregnant women who are dependent on opioids should be referred to a specialist for further advice. 

Upon referral, the woman will usually be advised to take a replacement opioid such as methadone.

All infants born to mothers who are suspected or known to abuse substances should be referred for screening for withdrawal symptoms. 

- Advise breastfeeding mothers not to use psychoactive drugs, and support them.
- Advise mothers with substance use disorders to breastfeed exclusively for at least the first six months, unless a specialist advises them not to breastfeed, an support them.
- Offer mothers who use harmful substances and young children social support services, if they are available, including additional postnatal visits, parent training and child care during medical visits.

Inform caregivers and other family members that asking about suicide often reduces the anxiety associated with the feeling; the person may feel relieved and better understood.

- Report and refer immediately  if it seems the person is at risk of harming him- or herself or others:
 - Immediately seek help from a supervisor or primary health care staff.
 - Don't leave the person alone.
 - Remove the means of self-harm.
 - Use skills in helping people feel calm.

General principles for the management of self-harm and suicide

Identify any suicidal thoughts or suicide attempts.

(See section 2.1.)  

If a person who self-harms must wait for treatment, do not leave him or her alone. Offer an environment that minimizes distress, if possible in a separate, quiet room with supervision and regular contact with a named staff member or a family member to ensure safety. Remove any means of self-harm, and consult a mental health specialist, if available.

Mobilize family, friends and other concerned individuals or community resources to monitor and support the individual during the immediate risk period.

Treat people who have self-harmed with the same care, respect and privacy as would be given to other people, and be sensitive to the probable emotional distress associated with self-harm.

If the person identifies friends and family who could provide support and whom he or she would like to have involved, encourage this.

Provide emotional support to relatives and caregivers if they need it. Suggest to caregivers that, even if they feel frustrated with the person, they should avoid hostility or severe criticism.

Refer when appropriate:

- Remain alert for situations that may require referral to a mental health specialist. These may include non-response to treatment, co-morbid physical or other mental health conditions and risk of self-harm or suicide.
- Be aware of the mental health services in the community, which might include counselling centres, psychologists, psychotherapists and governmental and nongovernmental organizations that provide mental health care and support.
- Discuss the possibilities with the person and involve them in the decision (e.g. "This would involve....", "Which option do you think would suit your needs?", "It seems that a number of things are making the job of parenting very difficult. You've mentioned many stressors, that you have difficulty in staying calm and that you and your partner often disagree about managing your child's disability. Is that right? I think that a tailored programme such as (name suitable programme in the community) would suit your and your family's needs...." "What do you think?"

KEY MESSAGES

- ➔ *Community workers can use a wide range of psychosocial interventions to support people affected by ZIKV and its complications in coping with stressors.*
- ➔ *At community level, people affected by complications associated with ZIKV should be assessed and given mental health care.*
- ➔ *Community workers should refer all people with severe mental health conditions and people at risk of self-harm, suicide or harming others to mental health professionals.*

LINKS TO RELEVANT RESOURCES

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of Zika virus: http://apps.who.int/iris/bitstream/10665/204492/1/WHO_ZIKV_MOC_16.6_eng.pdf?ua=1

mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings. Version 2.0: http://www.who.int/mental_health/mhgap/mhGAP_intervention_guide_02/en/

mhGAP humanitarian intervention guide: http://www.who.int/mental_health/publications/mhgap_hig/en/

Thinking Healthy: a manual for psychosocial management of perinatal depression (WHO generic field-trial version 1.0). Thinking Healthy Programme is a manual for psychological management of perinatal depression that has been adapted for peer delivery. It provides instructions on how to integrate the management of perinatal depression into the work of primary care staff and community agents. The peer delivery version is simplified, with additional strategies for peers (caregivers).

Sikander S, Lazarus A, Bangash O, Fuhr DC, Weobong B, Krishna RN, et al. The effectiveness and cost-effectiveness of the peer-delivered Thinking Healthy Programme for perinatal depression in Pakistan and India: the SHARE study protocol for randomised controlled trials. *Trials*. 2015;16:1–14:

http://www.who.int/mental_health/maternal-child/thinking_healthy/en/

Manual on community training for people with disabilities: <http://www.who.int/disabilities/publications/cbr/training/en/>

Parent skills training (available from WHO upon request). The programme is written for community workers, including parents and caregivers. It provides evidence-based training in skills for caregivers of children with developmental disorders and delays that can be used locally in low- and middle-income countries.

Malamulele Onward Carer-2-Carer Training Programme (C2CTP) provides primary caregivers (predominantly mothers and grandmothers) of children with cerebral palsy with basic information about the condition, with simple handling strategies which can be incorporated into everyday life, such as positioning, feeding, dressing, communicating and bathing: <http://cpchildren.org/>

Getting to Know Cerebral Palsy, by the London School of Hygiene and Tropical Medicine, is designed to provide knowledge and skills in caring for a child with cerebral palsy. The programme promotes participatory learning to empower parents and caregivers: <http://disabilitycentre.lshtm.ac.uk/files/2013/06/Getting-to-know-cerebral-palsy-v1-hires.pdf>.

Parent to Parent (P2P) promotes access to, the quality of and leadership in parent-to-parent support in the United Kingdom and the USA. The service is provided by trained volunteers who are parents of a child with a disability:

<http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>; <http://www.autism.org.uk/services/community/family-support/parent-to-parent.aspx>.

Contact a Family supports the families of disabled children by providing information, advice and support, bringing families together to support each other and campaign to improve their circumstances and for their right to be included and equal in society: <http://www.cafamily.org.uk>.

Creating peer support groups in mental health and related areas

<http://apps.who.int/iris/bitstream/10665/254813/1/WHO-MSD-MHP-17.13-eng.pdf>

3

MODULE



Rehabilitation and psychosocial support for people with Guillain Barré syndrome triggered by Zika virus

This module is designed to give community workers an understanding of how to provide rehabilitation for people affected by GBS as a result of ZIKV in the community and at home. Programmes for rehabilitation should be tailored for each individual, with consideration of both their physical and their mental health. Throughout rehabilitation, community workers should communicate with facility level providers (as described in the Manual for health care professionals, Module 2), who should continue medical supervision of the affected individual's progress.

- 3.1 Overview of Guillain Barré syndrome and stages in rehabilitation in the community and at home*
- 3.2 Preparing a plan for rehabilitation in the community and at home*
- 3.3 Rehabilitation interventions*
- 3.4 Psychosocial support*



Overview of Guillain Barré syndrome and stages in rehabilitation in the community and at home

GBS is an acute, potentially life-threatening medical condition, usually triggered by an infection, in which the body's immune system attacks nerves that control motor function and sensation (49). It can affect the muscles involved in speaking, swallowing and breathing and is a medical emergency requiring urgent referral and management in a health facility. (See Manual for health care professionals, Module 2).  

The medical complications and disability caused by GBS generally progress over a few days to several weeks. Recovery may be slow, and a minority of people affected by GBS are left with significant residual symptoms that result in long-term disability and prevent a successful return to their lifestyle or occupation. Most people affected by GBS eventually fully or nearly fully recover if they have optimal medical treatment. Many people affected by GBS walk after a few months and experience only minor residual symptoms by the end of the first year after onset.

Rehabilitation is an essential part of the care for people affected by GBS, the goal being to optimize function and reduce disability. Rehabilitation can be delivered in various settings, including the home, the community, the workplace or other settings (50). Rehabilitation is most effective when delivered by a multidisciplinary team.



LEARNING OBJECTIVES

- ➔ *Understand common experiences and challenges for people with GBS*
- ➔ *Understand the basic steps in planning an individual rehabilitation programme*

Recognition of acute GBS in the community



GBS is an acute, potentially life-threatening medical condition, usually triggered by an infection, in which the body's immune system attacks nerves that control motor function and sensation.

ZIKV has been identified as an infectious trigger of GBS.

Refer any person who presents with weakness or floppy limbs immediately to a hospital for further assessment and management. See Module 3 of the Manual for health care professionals for further information on the assessment and management of people with GBS.  

Common experiences and challenges for people with GBS

The experience of GBS for many people is characterized into three phases, with common symptoms:

- weakened muscles, which strengthen, often slowly, as the nerves heal;
- reduced sensation, with slow recovery to feel touch, pain and sense of position; the pain is associated with nerve healing;
- reduced mobility due to muscle weakness and decreased sensory input, which affects balance and can affect the person's ability to perform daily activities;
- fatigue, which can affect the whole person or their muscles;
- anxiety, depression, fear or other psychosocial concerns that may arise during severe and prolonged illness; the associated mental health and psychosocial effects should be recognized, as they can significantly affect recovery (see below and section 2.1);   and
- pain due to damaged nerves, which can be debilitating both physically and mentally.

The three phases of GBS are:


- An initial acute period, during which the condition may worsen. It can last for up to 4 weeks, although the peak is usually reached within 1–2 weeks. During this period, the person should be in a health care facility where he or she can be closely monitored. Some patients require intensive care. Fear and anxiety are common in both patients and caretakers during this phase, and both psychosocial support and medical care are required. (See section 2.1.)




- The plateau period, which may occur either in a health care facility or after returning home. The person's condition stabilizes during this period, over weeks to months. Frustration with the challenges of adjusting to the physical effects of GBS is common during this phase. Community workers should encourage the patient to engage in therapy and provide hope and encouragement when slow improvement discourages the person.
- Recovery phase, during which improvement is seen. Individuals can usually return to their routine activities, including work or school; however, many experience excessive fatigue, muscle weakness or muscle pain. Rarely, people with GBS remain significantly disabled. During this phase, affected people often fear the return to previous activities, and appropriate psychosocial support is needed. The pattern of recovery varies, and the person should be prepared for possible outcomes while being encouraged to maintain rehabilitation. A recovering person with both a functional disability and mental health or psychosocial needs may find it difficult to return to his or her occupation. Lack of employment may be a significant stressor. Setting realistic goals is essential for an effective programme.

Rehabilitation in the home and the community

A decision to provide rehabilitation at home or in the community depends on the needs of the affected individual and family. If such care is decided, a rehabilitation plan must be designed, which should be preceded by a comprehensive assessment, with frequent reassessments. It should include:

- identification of the psychosocial concerns of the affected person and his or her caregiver or family (see section 2.1); 
- assessment of the physical condition of the person, as the effects of GBS vary widely, and, if available, formal physical and occupational therapy assessments; and
- evaluation of the home environment and community support services.

The plan should be based on the person's current physical condition and individual needs, which he or she should acknowledge. Accommodate the person's preferences and choices without compromising the therapy. If the therapy requires specialized evaluation or treatment, refer when possible. 

The interventions should be tailored to each individual and the settings in which he or she lives, with advice and education throughout rehabilitation.

The results of rehabilitation should be monitored. This is integral to effective delivery, as the programme should be adjusted regularly on the basis of a needs assessment.

KEY MESSAGES

- ➔ *Rehabilitation is a crucial part of the continuum of care and should be provided as early and for as long as necessary.*
- ➔ *The recovery of people with GBS varies widely, including the length of recovery and issues such as fatigue and pain.*
- ➔ *A comprehensive, routine assessment is required for planning rehabilitation treatment, and every person should have a tailored rehabilitation programme.*



Preparing a plan for rehabilitation in the community and at home

In order to deliver an effective rehabilitation programme in the community and at home, an initial assessment should be performed to determine the person's concerns and priorities and so that he or she understands why particular exercises and advice are given.

Engaging people in planning their own treatment increases their motivation and is in line with the person-centred care approach.

When family members are involved in planning treatment, the individual will have support for day-to-day activities at home.

LEARNING OBJECTIVES

- ➔ *Be able to undertake an assessment before preparing a rehabilitation programme.*
- ➔ *Recognize the importance of including the individual and family members in preparing an effective treatment programme.*

Assessment


Once a patient is in the plateau and recovery phases, the community worker should conduct routine, frequent assessments to evaluate nerve recovery, functioning, physical pain and mental and social stressors.

If the person with GBS was admitted to a health facility during the initial acute period, he or she was probably assessed by a physiotherapist and an occupational or speech therapist. If this is the case, a discharge report, including advice on rehabilitation, may be available. Further specialist advice may be sought to assist the community worker in providing rehabilitation.

Assessments should include the following.

- Conduct initial interviews with the affected person and the caregiver to assess how the person is feeling and functioning and to identify any concern about recovery, including questions on the levels of pain and fatigue being experienced.
- Assess the person's ability to sense touch in each body section, by simply touching the skin lightly while the person is not looking and asking him or her to respond when touched.
- Inspect the person's skin. The skin may be damaged in areas with reduced sensation and also on bony prominences and weight-bearing structures.
- Assess the range of movement in joints, focusing on the joints of the hand, wrist, foot and ankle. Ask the patient to lift his or her arms and move the hands and wrists in and up and down, side to side and in circular movements. If the patient remains weak, the assessment can be done from "passive movement", in which the community health worker supports the limb, hand or foot and moves it in the usual directions. The results for the two sides of the body should be compared and also with what an average person can do in order to identify limitations in the range of movement. Such limitations can generally be addressed with interventions to increase mobility.
- Assess the person's muscle strength to guide the choice of exercises and progression of the programme.
- Difficulties in mobility, such as transferring from one point to another and walking pattern, should be identified to inform interventions and to determine whether assistive devices or modifications to the person's home are required.
- Observe and identify how well the person can complete daily activities, and ask about difficulties in self-care.
- Assessment of difficulties in speaking, swallowing and coughing indicates whether the vocal cords and pharyngeal muscles remain weak. Difficulties in coughing or swallowing increase the risk for aspiration and resulting chest infection. Ask the patient whether he or she experiences pain on swallowing or a feeling that food is getting stuck. Observe the person while he or she is speaking and swallowing to identify drooling and coughing.
- Assess the mental health and emotional needs of the person and family members. (See **Box 7** for specific questions to pose.)
- Assess the home and community environment to identify and then address any barriers, hazards and challenges. Assess the supportive infrastructure in the home environment, and consider cultural and spiritual influences on rehabilitation.

Planning treatment

- A treatment plan comprises exercises and advice for the person over the coming weeks or months. The community worker should expect to see the affected person regularly during this period, depending on need. The frequency may vary, but, initially, a weekly visit to the home or clinic is recommended.
- Treatment should be planned after a conversation with the person to determine his or her main concerns, goals and priorities.
- A treatment plan is likely to include advice and education for recovery, mobility exercises and advice for daily activities. It may include prescription of assistive devices and referral for specialist services and advice. 

KEY MESSAGES

- ➔ *Motor and sensory activities, swallowing, speech and limitations due to pain should be assessed in all patients, and the assessment should be repeated frequently, as the patient's symptoms and functional status may change rapidly.*
- ➔ *Also assess emotional and psychosocial needs.*
- ➔ *An individualized treatment plan should be prepared, which should involve caregivers.*



Rehabilitation interventions

This section addresses specific interventions to rehabilitate the physical and mental health of the affected person during recovery. While a comprehensive programme should ideally include components of all the interventions listed below, the time dedicated to each will depend on individual needs and should be designed to promote not only recovery but also reassurance.

LEARNING OBJECTIVES

- ➔ *Recognize the main interventions for improving mobility, functioning, swallowing, speech, pain and fatigue.*
- ➔ *Recognize the steps required to prepare the person to return to school, a job or community activities.*
- ➔ *Be able to decide how long to continue rehabilitation.*

Interventions for limited mobility

Mobility is an individual's capacity to move from one point to another, such as transferring from bed to chair, walking independently or running. The general advice for increasing mobility is to keep trying to move and to return to one's usual activities. Thus, people should be encouraged to perform their usual everyday activities at home and in the community. The basic principle is to encourage a gentle increase in activity without significant pain or fatigue. The levels of pain and fatigue should guide the amount of activity, as excess of either is unhelpful for recovery.

The recovery of people with GBS on their return to the community varies. If transferring in and out of chairs, beds and cars and walking short distances remains a challenge, an assistive device may be required initially. If walking remains difficult, a walking frame may be needed for support, but the amount of support from the device should be reduced as the person regains strength. For example, a person who initially uses a walking frame may change to a walking stick as they become stronger.

If basic mobility, including transferring in and out of bed and walking, is very difficult, a wheelchair may be required. A wheelchair is usually needed only for a certain time but could be used to help a person to leave their home or travel longer distances.

An important intervention for improving mobility is the provision of advice to both the person and the family. Family members should be advised on how best to support transfers and mobility, including on basic lifting techniques and body mechanics to decrease the risk for injury to themselves and to the person. Advice on how to avoid falls is summarized in the section on making the home environment safe.

The goal of muscle exercises is to achieve optimal muscle strength while the nerves are recovering. Muscle strength returns with nerve recovery, and exercises should be linked to the recovery rate. Some repetitive muscle exercises that encourage a wide range of movement could be prescribed. Basic guidance for exercises is to increase repetition before increasing the resistance, weight or difficulty of the exercise. As strength returns, a household object such as a tin of beans or a bag of rice can be used for weight resistance.

Weakness in the leg muscles may result in "foot drop", in which the foot drags and the toes are pointed downwards when the person lifts a foot while stepping. This may improve rapidly; if not, an ankle-foot orthosis should be prescribed by referral to a prosthetic and orthotic service, if available.

Interventions for daily activities

Interventions to support daily activities should be based on the person's demands in the home and at work and his or her recreational interests and support system. Observational assessment is helpful for identifying difficulties in the home environment. This should include:

- looking for difficulty in moving up and down stairs, which might require adaptation such as placing a bed on the ground floor, placing a rail on the wall near a step and moving furniture out of the way;
- adapting cooking or eating utensils, for example, increasing the diameter of utensil handles to facilitate grip;
- adapting the bathroom as much as possible to increase independence, for example, by placing a plastic chair in a shower, keeping the area clear of obstacles and acquiring a commode chair; and
- looking for potential hazards to ensure safety by avoiding falls or burns in the home, such as hot water taps that are difficult to turn, loose wires, uneven floor coverings, steps and furniture that are obstacles to movement.

People recovering from GBS should be encouraged to return to their daily activities as soon as they can. Difficulty in performing an activity can be overcome by adapting both the activity and the environment. Caregivers and other family members can be trained to help affected people to adjust their activities in the home.

Interventions to address difficulties in swallowing and speech

If the person had difficulty in coughing or swallowing while in hospital, he or she is at risk for the persistence of some degree of difficulty during the recovery phase. People who report difficulties in swallowing or coughing or coughing while swallowing are at risk for aspiration and should be referred to a speech therapist for assessment. The basic advice is to eat carefully and slowly and to identify early signs of a chest infection. Speech therapists can propose modified diets that reduce the risk for aspirating food into the airways while swallowing.

When weakness in the vocal cords is observed, as reduced volume, the basic advice is to reassure the person that the symptom will usually resolve over time and the muscle strength in their vocal cords will return at the same time as the muscle strength in their arms and legs; they should use their voice gently, without overstraining it.

Interventions to prevent damage to the skin

A person who has lost skin sensation is at high risk for damage to the skin as he or she is unable to feel the pain of skin damage. Such people must be advised to avoid activities that could result in burns, cuts or prolonged pressure on the area of skin that lacks sensation. The location of sensation loss, for example, the feet or hands, will determine the practical advice that should be given. Feet are potentially at greatest risk, and protective shoes are important.

Interventions for pain

Pain specifically related to healing of nerves, neuropathic pain, is frequent in all phases of GBS. It is often ignored and is usually undertreated. When people are on medication for nerve and muscle pain, the community worker should consult the health care facility to adjust the doses as required during recovery. Other treatments, such as applying heat or cold, gentle exercise and relaxation techniques, may be helpful in managing pain. The person should, however, have realistic expectations about pain control, as therapeutic interventions (both medical and nonpharmacological) may result in only minimal or moderate improvement. People should work to manage their pain rather than be managed by their pain.



Pain during the recovery phase is typically burning, stabbing or shooting. It may be associated with marked sensitivity to touch, so that even the light touch of bed sheets is perceived as pain. Pain may be exacerbated by exercise and weight-bearing and thus interfere with rehabilitation.

Neuropathic pain usually subsides with time; however, some degree may persist for months or years, and some may be permanent. People with persistent pain should be referred to a health facility for specialist advice and prescription of neuropathic pain medicine.

Interventions for fatigue (51)

Fatigue is a common health condition in all phases of GBS, particularly in the recovery phase. Strategies to manage fatigue include conserving energy such as by pacing oneself and separating tasks into steps. Assistive devices to facilitate the performance of daily activities may increase energy and thereby lessen the symptoms of fatigue.

A person who feels fatigue should have good-quality sleep in the afternoon rather than doze lightly and should therefore go to bed in a darkened room. The sleep is likely to be deeper, of better quality and more energizing.



Training in coping strategies, balancing mental and physical activities and rest may improve wellbeing. The effect of exercise programmes on the level of fatigue has been investigated in several studies. **Intervention H** provides practical tools. (See section 2.2.)  



Interventions for returning to work

Returning to work is an important step forward for people who have experienced GBS, and they should be encouraged to return to all activities when they feel ready. The presence of any residual conditions and the work itself will determine whether any support or modifications to the workplace are required. If they are, the person should be assessed while performing tasks to determine what advice and interventions should be provided. Occupational therapists are specialists in supporting people in their return to work, and referral for their assessment is suggested if residual health issues persist.

Fatigue may remain for some time, including when people are ready to return to work. They should be advised to do so gradually, with a stepped increase in the number of working days based on monitoring of fatigue. Strategies to conserve energy should be used. Similar advice should be given to an adult or child returning to education after GBS.

Interventions for returning to community and recreational activities



A return to normal social activities within the family and the local community should be encouraged. (See **intervention C** in section 2.2.)   Caregivers and families can help to ensure that people attend social activities and feel included in the community.

Peer support groups (see section 2.2)   can be important for socializing with others who understand the challenges they are facing and can offer support in coping with changes in daily living.

A return to recreational activities is also important, although advice on modifying activity may be required, especially strategies to conserve energy and avoid fatigue.

Interventions for promoting mental wellbeing

Community workers should always be encouraging and hopeful about a person's recovery, without making promises about the extent of recovery or the time frame (51), although the large majority of people return to a good level of functioning.

Be alert to potential anxiety and depression as a result of GBS. (See section 2.1.)   Referral to support groups and linkage with a national association for GBS can also provide support. (See **Box 11**.)

Monitoring and review of treatment interventions

The effect of interventions for people with GBS should be monitored to ensure that the exercises prescribed are appropriate and do not damage tissue or overly fatigue the patient. The community worker should see GBS patients regularly to understand their perspectives. Motivation and psychosocial status should be monitored continuously, with encouragement and support.

Planning discharge from the community health service system

People with GBS should receive all the rehabilitation they need. As they recover and their everyday functioning returns to pre-GBS levels, discharge from the community health service system should be planned. They should receive all the necessary information and advice, including where to go if further problems arise.

Interventions for long-term support

Community workers should recognize the stress associated with the inability to work during the illness and can help patients to address issues such as reduced income and then support them in returning to their job or school by linking them with services in the community.

They may consider referring people to vocational training if they cannot return to their previous type of work. They should encourage people to find new activities and occupations that they may find enjoyable. Community workers could also engage with employers to allow a stepped return to work.

People with GBS usually experience some degree of disability during the illness, and a small percentage continue to have difficulties in functioning or experience disability over a long period. Understanding disability is important. Everyone is vulnerable to becoming disabled, particularly in later life. Furthermore, people with disability commonly experience stigma and discrimination, as well as barriers in the environment. People with a disability have the same rights as anyone else, and actions to address negative attitudes, remove barriers and increase social inclusion should be promoted. Linking people with disability services such as appropriate support groups and disabled people's organizations can be positive.

KEY MESSAGES

- ➔ *Specific interventions to improve mobility, functioning and daily activities, swallowing and speech and to reduce pain and fatigue should be part of a tailored rehabilitation programme for each individual.*
- ➔ *The effects of interventions on functioning and overall recovery should be monitored regularly and adjustments made as necessary.*



Psychosocial support

People affected by GBS were often previously healthy and now face difficulties in functioning, which often affects their daily activities. The emotions felt during the phases of the illness can cause significant distress. A small number of people with GBS may have persistent difficulties in functioning. Thus, the entire course of the illness, recovery and readjustment to daily life often causes significant stress for both the affected person and his or her family. This can affect recovery if it is not recognized and properly supported. Community workers can provide effective, supportive information, link people affected by GBS and their caregivers to medical and supportive care and ensure that the affected person has emotional and physical support at all stages. Some people may benefit by consulting a mental health professional, and this should be evaluated regularly.

LEARNING OBJECTIVES

- ➔ *Be aware that people and their caregivers might have different psychosocial stressors and reactions at different stages of GBS.*
- ➔ *Be able to identify warning signs of severe mental health conditions that require consultation or referral to a mental health professional in the community.*

GBS can be a challenging experience, with various emotions felt throughout the illness. Affected people and their caregivers often feel overwhelmed, confused and uncertain about what is happening. They may feel fearful and anxious or numb and detached. Some people have mild reactions, while others may have more severe conditions. In general, how people reacts depends on many factors, including:


- the nature and severity of the symptoms;
- their experience with previous distressing events;
- the support they have from others;
- their general physical health;
- their personal and family history of mental health problems;
- their cultural background and traditions; and
- their age.


Emotions and needs for mental health and psychosocial support according to the phase of illness

Acute phase: During this phase, the person requires support for medical complications and progressive weakness in a health care facility. They may, however, have been initially identified as having GBS by a community worker, so that the link will be continued when the person returns home. This can optimize long-term care strategies.

The community worker should recognize that the acute phase of GBS can be challenging for everyone. The family is likely to experience fear, grief and tension. In these difficult moments, more than ever, it is essential to treat everybody with respect and contribute to an atmosphere of dignity for all. The situation can be frightening, and the community worker should explain why the person must go to hospital and the risks of not going to hospital.



Affected people may have various feelings, fear and anxiety being the most common. Initially, they will have many concerns, including whether the condition will worsen, whether

they will ever be able to walk again or do the activities they once were able to do. (See section 1.1.)  The community worker should always be encouraging and hopeful regarding a person's recovery, without making promises about the extent of recovery or the time frame. He or she should acknowledge that the person has gone from being completely independent to experiencing at least some degree of dependence on others and the wide array of emotions that this can engender.

Plateau phase: During this phase, when people are stabilizing and preparing to return home or to the community, they require support. The community worker should listen to the family's concerns and respond to their practical needs by linking them to available community resources. This will assure better long-term care at home when done in the early phase of the illness. (See section 2.2, **Interventions C and D.**)  Family members could be encouraged to form or attend a peer support group.



Communication with the health care team will facilitate smooth transition of care when the person returns home. Services, including psychosocial services for the person and caregivers, a plan for rehabilitation, rehabilitation care and home services, should be arranged while the patient is still in hospital, by coordination between the health care facility and the community.

Recovery phase: As the person begins to regain function, many new stressors may arise, including fear about the rate of recovery, anxiety about resuming previous roles at work or school and depression or guilt about the cost of the illness, particularly during slow recovery.

The community worker should recognize that people tend to cope better when they have friends, family members or community groups who offer care and support. For individuals with minimal support, provide contacts such as support groups and support through ones own networks. (See section 2.2, **intervention C.**)  Help the person to access the services and to connect with social support, including individual counselling if available. (See section 2.2, **intervention D.**) 

People in the recovery phase of GBS should attempt to return to their daily lives. With modifications, persons should be able to do the activities they previously enjoyed. Maintaining a daily routine is essential to their reintegration into their community.



Many people go through a period of low motivation for participating in their home rehabilitation plan. The best way to help increase motivation is to let the person know that he or she is not alone and continue to involve him or her in decisions on care.

At all phases, discuss stress and positive coping methods with caregivers. Remind them that stress is a normal, common response to difficult situations, and help them to recognize warning signs of stress early so as to strengthen positive coping methods. (See section 2.2, **intervention E**.)  

Stigma and discrimination can negatively affect both psychosocial wellbeing and reintegration of people with GBS in their communities. Service providers should contribute to dispelling myths about the condition.

Be alert to symptoms and signs suggesting a mental health problem. People affected by GBS should be screened routinely for thoughts of self-harm. Remember that asking about self-harm does not provoke them to act. If there is any concern about self-harm, a mental health professional should be consulted urgently, advise the family not to leave the person alone, and remove all possible means of self-harm.

TABLE 7. PSYCHOSOCIAL INTERVENTIONS BY PHASE OF GBS  

Phase	Relevant psychosocial interventions
Acute	<ul style="list-style-type: none"> • Supportive communication (See section 2.2, intervention A) • Identify and respond to immediate needs and concerns (See section 2.2, intervention B) • Link to individual and family social support (See section 2.2, intervention C) • Discuss positive coping methods (See section 2.2, intervention E) and stress management (See section 2.2, intervention F) • Consult a mental health professional
Plateau	<ul style="list-style-type: none"> • Supportive communication (See section 2.2, intervention A) • Discuss positive coping methods (See section 2.2, intervention E) and stress management (See section 2.2, intervention F) • Link to community resources and services (See section 2.2, intervention D) • Consult a mental health professional
Recovery	<ul style="list-style-type: none"> • Discuss positive coping methods (See section 2.2, intervention E) and stress management (See section 2.2, intervention F) • Assessment for severe conditions and management or referral as appropriate (See section 2.3)   • Link to community resources and services (See section 2.2, intervention D) • Discuss problems-solving techniques (See section 2.2, intervention G) • Attend peer support groups in the community, if available. • Consult a mental health professional

KEY MESSAGES

- ➔ *At different stages of GBS, people and their caregivers might have different psychosocial stressors and reactions.*
- ➔ *The acute nature of GBS can lead to a wide range of reactions at different stages of the condition. Community workers should be able to link people affected by GBS to available resources, provide supportive communication and psychosocial support.*
- ➔ *At community level, people affected by complications associated with ZIKV, including GBS, should be assessed for and provided with mental health care.*

LINKS TO RELEVANT RESOURCES

WHO. Community-based rehabilitation: <http://www.who.int/disabilities/publications/cbr/en/>.

WHO. Guidelines on provision of manual wheelchairs in less resourced settings: <http://www.who.int/disabilities/publications/technology/wheelchairguidelines/en/>.

WHO. Priority assistive products list: http://www.who.int/phi/implementation/assistive_technology/EMP_PHI_2016.01/en/.

Psychosocial support for pregnant women and for families with microcephaly and other neurological complications in the context of Zika virus: http://apps.who.int/iris/bitstream/10665/204492/1/WHO_ZIKV_MOC_16.6_eng.pdf?ua=1.

Psychological first aid guide for field workers: http://www.who.int/mental_health/publications/guide_field_workers/en/.

mhGAP Intervention guide for mental, neurological and substance use disorders in non-specialized health settings: http://www.who.int/mental_health/publications/mhGAP_intervention_guide/en/.

mhGAP humanitarian intervention guide: http://www.who.int/mental_health/publications/mhgap_hig/en/.

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**WHO TOOLKIT FOR THE CARE AND SUPPORT OF PEOPLE
AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS**

Manual for community workers

This manual is designed for community workers who are responsible for direct care, monitoring and following up children with or at risk of congenital Zika virus syndrome, people with Guillain Barré syndrome and other associated complications, as well as caregivers and families. The manual provides practical guidance for coordinated, community-based care in partnership with other facilities and existing resources.

The manual contains the following modules:

1. Providing care and support for children in a Zika virus-affected area
2. Psychosocial support for caregivers and families of children with or at risk for congenital Zika virus syndrome
3. Rehabilitation and psychosocial support for people affected by Guillain Barré syndrome triggered by Zika virus

Community workers should know when and how to refer people affected by complications associated with Zika virus for additional assessment and management; see the Manual for health care professionals.  For information required to coordinate care and support for people affected by complications associated with Zika virus refer to the Manual for public health planners and managers. 

WHO TOOLKIT FOR THE CARE AND SUPPORT OF PEOPLE AFFECTED BY COMPLICATIONS ASSOCIATED WITH ZIKA VIRUS

Zika virus is associated with severe neurological complications, particularly congenital Zika virus syndrome and Guillain Barré syndrome. The associated complications have a marked impact on the people affected and their communities, including both physical and mental health.

The WHO Toolkit for the care and support of people affected by complications associated with Zika virus has been developed to serve as a model guide, with the goal of enhancing country preparedness for ZIKV outbreaks. The toolkit is designed to provide a systems approach enabling public health planners and managers to identify necessary infrastructure and resources, as well as technical and practical guidance for health care professionals and community workers.



Manual for public health planners and managers

MODULE 1:
Essential information on complications associated with Zika virus

MODULE 2:
Strengthening the long-term response to Zika virus



Manual for health care professionals

MODULE 1: Management of children born in Zika virus-affected areas

MODULE 2: Assessment and management of people with Guillain Barré syndrome and other neurological complications triggered by Zika virus

MODULE 3: Mental health and psychosocial support for people affected by complications associated with Zika virus



Manual for community workers

MODULE 1: Providing care and support for children in a Zika virus-affected area

MODULE 2: Psychosocial support for caregivers and families of children with or at risk for congenital Zika virus syndrome

MODULE 3: Rehabilitation and psychosocial support for people affected by Guillain Barré syndrome triggered by Zika virus



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