



# Birth Defects and Childhood Disability Toolkit

## Section 7 - Birth defects services



**Birth Defects Research Foundation, Pune, India**

*A research NGO working for evidence based policies and advocating for the rights of children with disabilities caused by congenital, developmental and genetic disorders*

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## 7.1 Maternal services for congenital disorders

### 1. Required maternal health services

#### 1.1 Preconception services

- ✓ Providing awareness about birth defects, prevention and protection
- ✓ Screening of all women intending pregnancy
- ✓ Management of women at higher risk of pregnancy complications
- ✓ Folic acid supplementation
- ✓ Rubella immunization
- ✓ Screening for prevalent genetic disorders

#### 1.2 Antenatal services

- ✓ Reinforcing need for routine antenatal care
- ✓ Compulsory prenatal (ultrasound) screening
- ✓ Counselling for women detected with a fetal anomaly or a positive prenatal test
- ✓ Counselling about medical care and early intervention services



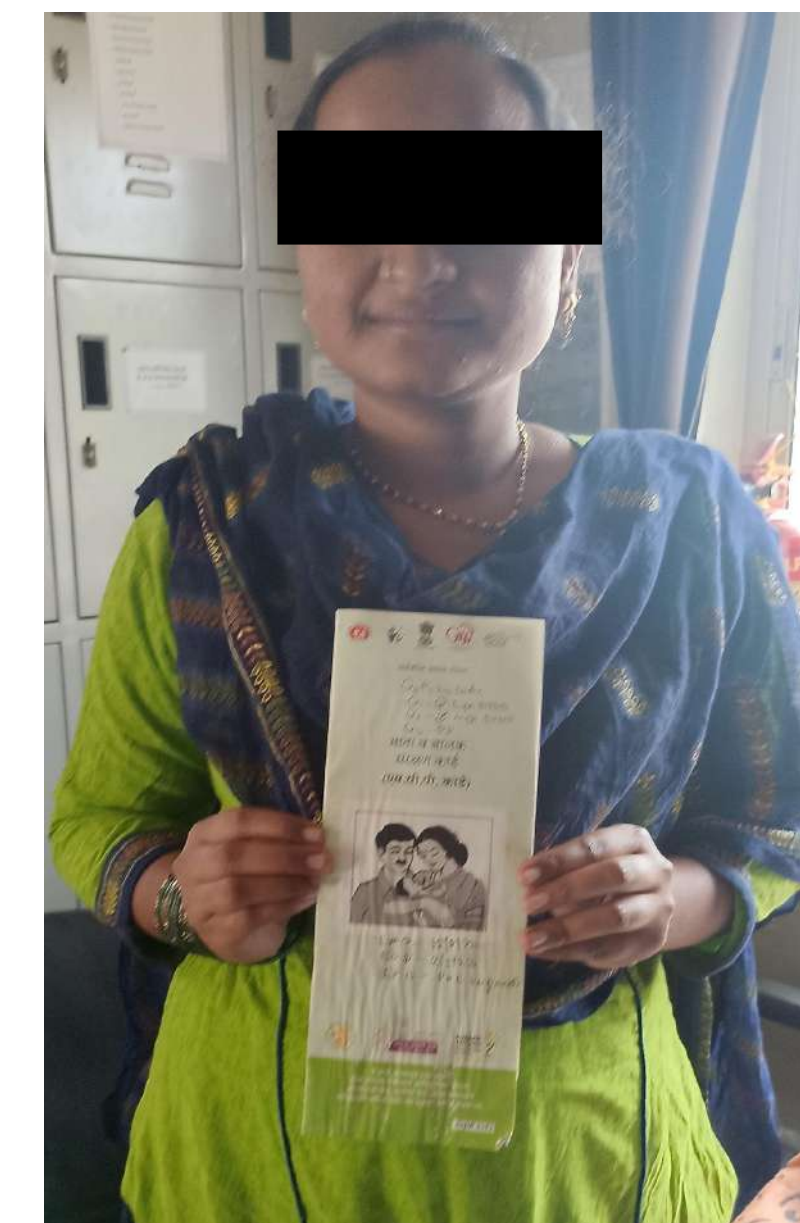
### 2. Services existing in India

#### 2.1 Preconception services

- A first programme has been rolled out in Maharashtra state, including provision of folic acid supplements
- Screening and management of women at higher risk of pregnancy complications (PMSMA)
- Sickle cell disease screening camps

#### 2.2 Antenatal services

- Screening for high risk pregnancies on the 9<sup>th</sup> of each month (PMSMA)
- Referral to higher level of services for management
- Prenatal ultrasound scans
- Medical termination of pregnancy is legal  
([poster 6.5 Abortion legislation for malformation affected pregnancies in India](#))



### References

([https://nhm.gov.in/images/pdf/programmes/RBSK/Resource\\_Documents/Guidelines\\_on\\_Hemoglobinopathies\\_in%20India.pdf](https://nhm.gov.in/images/pdf/programmes/RBSK/Resource_Documents/Guidelines_on_Hemoglobinopathies_in%20India.pdf)); ([https://nhm.gov.in/images/pdf/programmes/child-health/annual-report/Two\\_Year\\_Progress\\_of\\_SNCUs-A\\_Brief\\_Report\\_\(2011-12\\_&\\_2012-13\).pdf](https://nhm.gov.in/images/pdf/programmes/child-health/annual-report/Two_Year_Progress_of_SNCUs-A_Brief_Report_(2011-12_&_2012-13).pdf)); ([https://nhm.gov.in/images/pdf/programmes/jssk/guidelines/guidelines\\_for\\_jssk.pdf](https://nhm.gov.in/images/pdf/programmes/jssk/guidelines/guidelines_for_jssk.pdf))



## 7.2 Abortion legislation for malformation affected pregnancies in India

Abortion laws and rights are regulated by the **Medical Termination of Pregnancy Act**. Law amended in 2021, currently known as the **MTP Amendment Act, 2021**

**ABORTION IS LEGAL IN INDIA. ELECTIVE TERMINATION OF PREGNANCY IS A WOMAN'S RIGHT**

### 1. What does the law permit?

- ✓ Pregnancy can be terminated up to **20 weeks** if there is a risk to the mother or if there is “a **substantial risk that if the child is born it would suffer from such physical or mental abnormalities to be seriously handicapped**”



### 2. For foetal malformations

- ✓ Abortion is permitted even after 24 weeks in case a **substantial fetal malformation** is detected
- ✓ **But .....** decision has to be forwarded to and approved by a Medical Board consisting of a gynaecologist, a pediatrician, a radiologist or sonologist.

### 3. Whose consent will be required for the procedure?

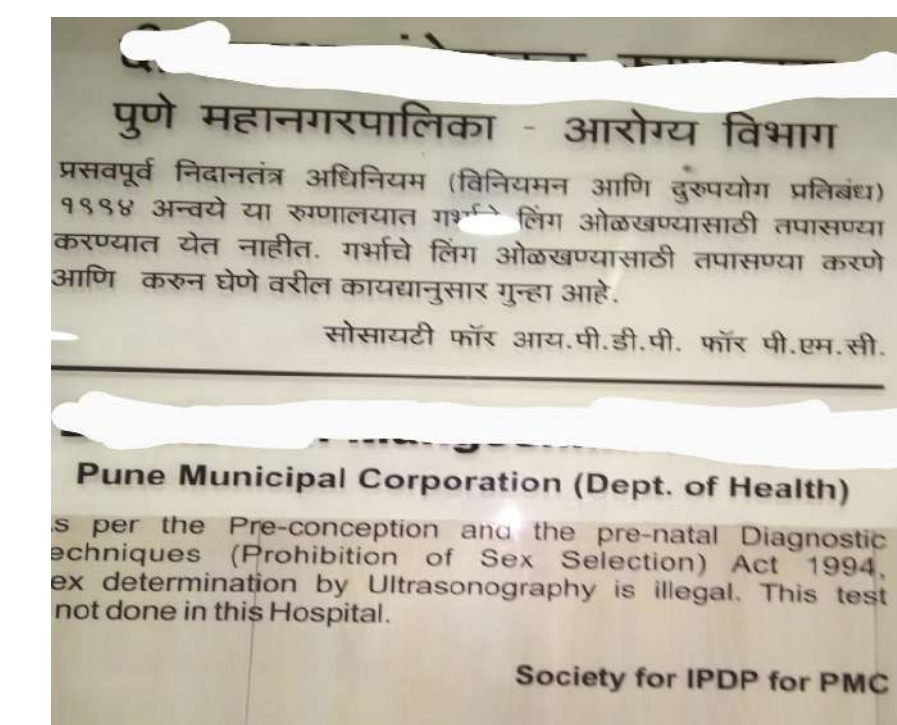
- ✓ Only the woman's signature is needed to provide consent. Signature of spouse is not needed.
- ❓ **Unmarried women** can also opt for **termination of pregnancy**.
- ❓ **Confidentiality is ensured**. Particulars (including name and other details) are kept confidential, and reported by the practitioner and the hospital **only to authorities**.

**4. BUT..... Abortion is not on request in India. The final decision is made by health care providers.....**

- ✓ If abortion has to be done **within 20 weeks of pregnancy**, opinion of **one registered medical practitioner** is needed,
- ✓ If abortion has to be conducted **between 20 to 24 weeks of pregnancy**, recommendation of **two registered medical practitioners** is necessary.
- ✓ In case of minor, or intellectually impaired women, signature of parent/guardian is required.
- ✓ For sex- linked disorders, test results are declared as positive or negative without mentioning fetal gender.

**5. Due to skewing of the sex ratio, sex determination tests are prohibited in india under the PCPNDT Act**

The **Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act 2003 (PCPNDT)** prohibits sex selection before conception. A pre-natal diagnostic test can be conducted to detect chromosomal abnormalities, genetic metabolic diseases, haemoglobinopathies, sex-linked genetic diseases, and congenital anomalies only by **authorized laboratories**.



There are limited studies on women's knowledge about abortion laws and rights for malformation affected pregnancies in LMICs where termination of pregnancy is legal

#### Reference

<https://egazette.nic.in/WriteReadData/2021/226130.pdf>

<https://pndt.gov.in/WriteReadData/l892s/PC-PNDT%20ACT-1994.pdf>



## 7.3 Child health services for congenital disorders

### 1. Child health services (for early detection and referral for medical care and rehabilitation)



#### Required services (integrated with maternal and child health programme)

- Newborn and child screening
- Developmental monitoring and investigation of developmental delay
- Education of caregivers on developmental milestones
- Medical, surgical and other specialist care
- Early intervention and referral for rehabilitation
- Routine child health services

### 2. Services existing in India

#### 2.1 Newborn screening for visible birth defects

#### 2.2 Care for Newborns requiring intensive care

- Newborn stabilization units at sub-district hospitals, special newborn care units, and newborn intensive care units
- Transportation for mother and child to tertiary level facility
- Free diagnostic and treatment services

**2.3 Community based monitoring : Home visits** by community health workers and follow up of babies discharged from intensive care units (ASHA)

#### 2.4 Community based screening RBSK child screening service and further

Referral to **DEIC** for medical and rehabilitation care (poster 8.3 The Rashtriya Bal Swathya Karyakram (RBSK) programme in India and 8.4 District Early Intervention Centre)

#### 2.5 Disability Schemes

(poster 7.5 Welfare Services for Persons with Disabilities in India and 7.6 Disability Registration in India)



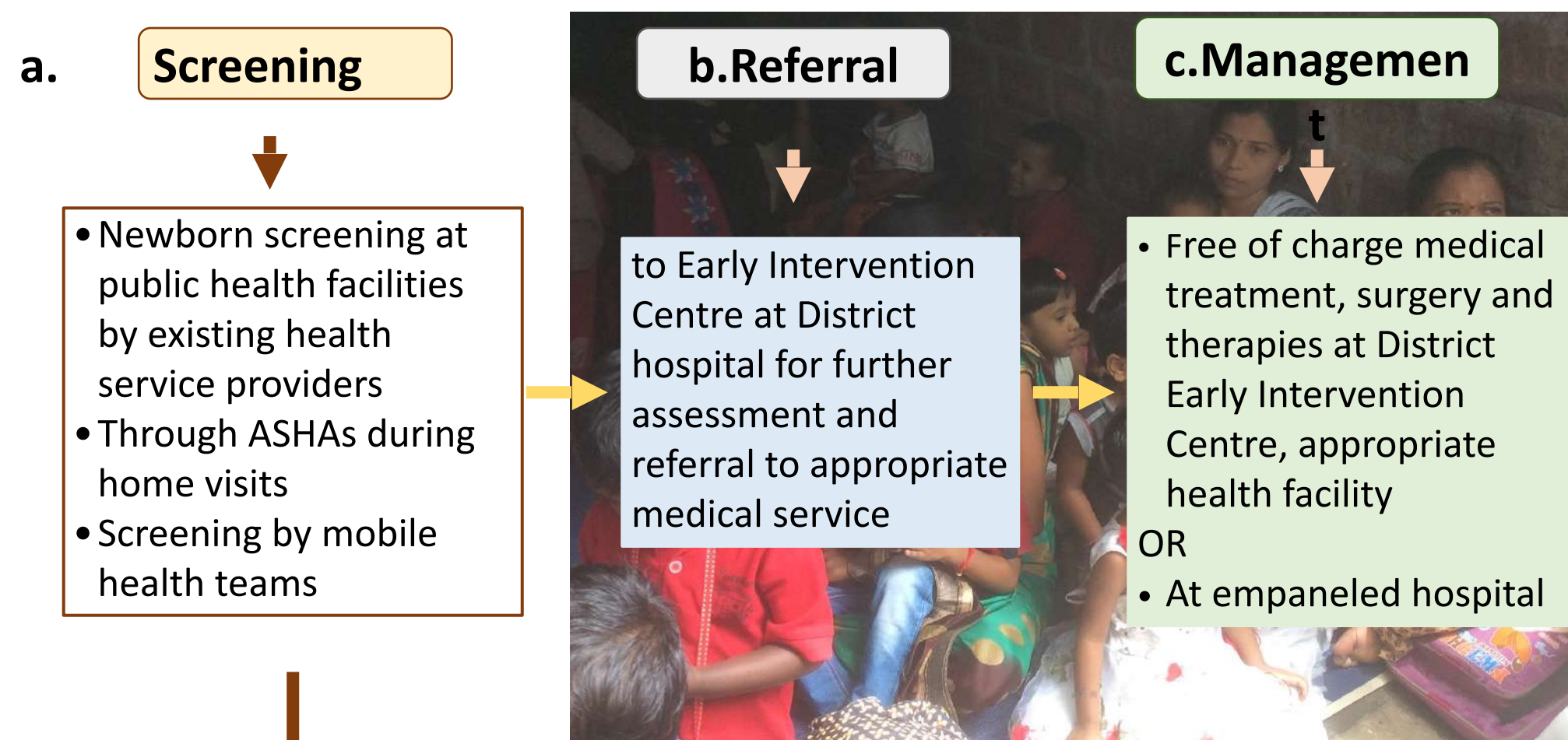
#### References

([https://nhm.gov.in/images/pdf/programmes/RBSK/Resource\\_Documents/Birth\\_Defects\\_Handbook.pdf](https://nhm.gov.in/images/pdf/programmes/RBSK/Resource_Documents/Birth_Defects_Handbook.pdf)); (<https://nhsrcindia.org/sites/default/files/2021-05/Helping%20ASHAs%20Identify%20Birth%20Defects%20English.pdf>)



## 7.4 The Rashtriya Bal Swasthya Karyakram (RBSK) programme in India

- RBSK is a community based child health screening and early intervention programme
- Mobile medical teams conduct screening at anganwadis (preschools) and government schools
- Three steps



Screening for 30 conditions

- Eligible age group 0-18 years
- At anganwadis (play schools) and government schools

### Conditions included in the programme

Identified Health Conditions for Child Health Screening and Early Intervention Services	
<b>Defects at Birth</b> <ol style="list-style-type: none"> <li>1. Neural Tube Defect</li> <li>2. Down's Syndrome</li> <li>3. Cleft Lip &amp; Palate / Cleft Palate alone</li> <li>4. Talipes (club foot)</li> <li>5. Developmental Dysplasia of the Hip</li> <li>6. Congenital Cataract</li> <li>7. Congenital Deafness</li> <li>8. Congenital Heart Diseases</li> <li>9. Retinopathy of Prematurity</li> </ol>	<b>Deiciencies</b> <ol style="list-style-type: none"> <li>10. Anaemia especially Severe Anaemia</li> <li>11. Vitamin A Deficiency (Bitot spot)</li> <li>12. Vitamin D Deficiency (Rickets)</li> <li>13. Severe Acute Malnutrition</li> <li>14. Goiter</li> </ol>
<b>Childhood Diseases</b> <ol style="list-style-type: none"> <li>15. Skin conditions (Scabies, Fungal Infection and Eczema)</li> <li>16. Otitis Media</li> <li>17. Rheumatic Heart Disease</li> <li>18. Reactive Airway Disease</li> <li>19. Dental Caries</li> <li>20. Convulsive Disorders</li> </ol>	<b>Developmental Delays and Disabilities</b> <ol style="list-style-type: none"> <li>21. Vision Impairment</li> <li>22. Hearing Impairment</li> <li>23. Neuro-Motor Impairment</li> <li>24. Motor Delay</li> <li>25. Cognitive Delay</li> <li>26. Language Delay</li> <li>27. Behaviour Disorder (Autism)</li> <li>28. Learning Disorder</li> <li>29. Attention Decit Hyperactivity Disorder</li> </ol>
<ol style="list-style-type: none"> <li>30. Congenital Hypothyroidism, Sickle Cell Anaemia, Beta Thalassemia (Optional)</li> </ol>	

Screening

Evaluation tools

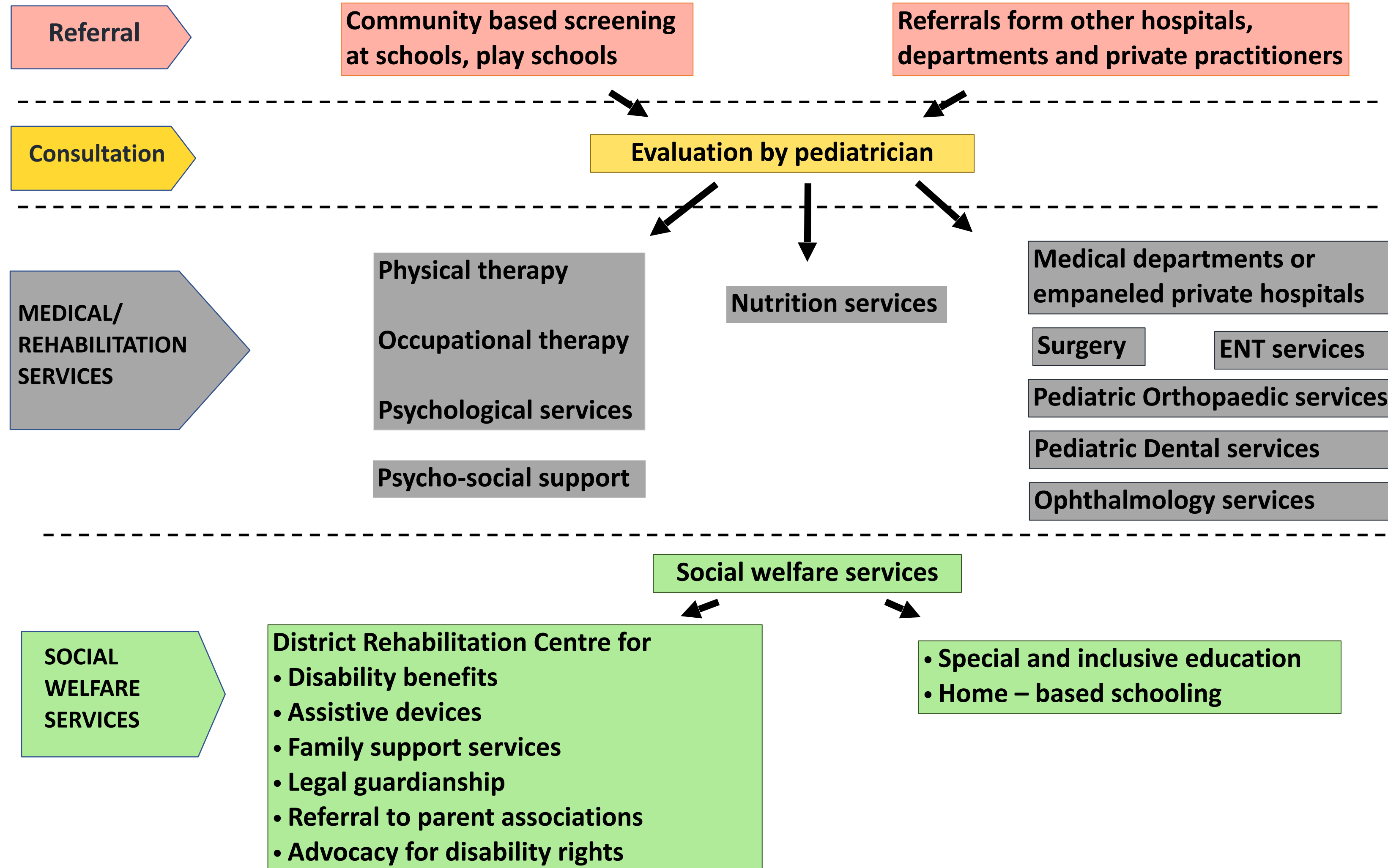
Guidelines

**References**  
<https://nhm.gov.in/index1.php?lang=1&level=5&sublinkid=1193&lid=372>; <http://nhmharyana.gov.in/WriteReadData/RBSK/RBSK%20Resource%20Material.pdf>



## 7.5 District Early Intervention Centre (DEIC)

1. District Early Intervention Centres are referral points for early intervention and management of children with birth defects, developmental disabilities, and nutritional deficiencies.
2. Services are provided according to the following plan



### References

(<https://nhm.gov.in/index1.php?lang=1&level=5&sublinkid=1193&lid=372>);  
 Kar, A., Radhakrishnan, B., Girase, T., Ujagare, D., & Patil, A. (2020). Community-based screening and early intervention for birth defects and developmental disabilities: lessons from the RBSK programme in India. *Disability, CBR & Inclusive Development*, 31(1), 30-46.