2025

CHILDREN WITH DISABILITIES IN MADHYA PRADESH (MP)

Working Paper 1: Access to Health, Nutrition and Therapeutic Services

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Submitted to UNICEF (Bhopal) Office

Abbreviations

AAMs	:	Ayushman Arogya Mandirs
AB PM-JAY	:	Ayushman Bharat Pradhan Mantri Jan Arogya Yojana
ADIP	:	Assistance to disabled persons for purchasing / fitting of aids / appliances
ALIMCO	:	Artificial Limbs Manufacturing Corporation of India
ARI	:	Acute Respiratory Infection
AT	:	Assistive Technology
BFA	:	Beneficiary Facilitation Agencies
CBR	:	Community-based Rehabilitation
CCIs	:	Child Care Institutions
CHO	:	Community Health Officer
CHW	:	Community Health Worker
CRC	:	Composite Regional Centres
CSR	:	Corporate Social Responsibility
CWSN	:	Children With Special Needs
DDRC	:	District Disability Rehabilitation Centres
DDRC	:	District Disability Rehabilitation Centres
DDRS	:	Deendayal Disabled Rehabilitation Scheme
DEIC	:	District Early Intervention Centres
DHFW	:	Department of Health and Family Welfare
DMHP	:	District Mental Health Program
DMT	:	District management Team
DoEPwD	:	Department of Empowerment of Persons with Disabilities (Divyangjan)
ECT	:	Electroconvulsive Therapy
ENT	:	Ear, Nose, and Throat
GIA	:	Grant in Aid
GPDP	:	Gram Panchayat Development Plan
GoI	:	Government of India
GoMP	:	Government of Madhya Pradesh
HBR	:	Home-Based Rehabilitation
ICDS	:	Integrated Child Development Services
IRDAI	:	Insurance Regulatory and Development Authority of India
IT	:	Information Technology
LCDIDC	:	Leonard Cheshire Disability and Inclusive Development Centre
LSUQ	:	Lok Sabha Unstarred Question
MHCA	:	Mental Healthcare Act
MHPs	:	Mental Health Professionals
MHRB	:	Mental Health Review Boards
MHT	:	Mobile Health Team
MP	:	Madhya Pradesh
NDN	:	National Disability Network
NFHS	:	National Family Health Survey
NDN	:	National Disability Network
NFHS	:	National Family Health Survey
NGOs	:	Non-governmental Organizations
NHM	:	National Health Mission
NILRED	:	National Institute of Labour Economics Research and Development
NIs	:	National Institutes
NMHP	:	National Mental Health Program
NPCBVI	:	National Programme for Control of Blindness and Visual Impairment
NPPCD	:	National Programme for Prevention and Control of Deafness
NR	:	Nominated Representative
OOPE	:	Out Of Pocket Expenditure
PM-ABHIM	:	Pradhan Mantri Ayushman Bharat Health Infrastructure Mission
RBSK	:	Rashtriya Bal Swasthya Karyakram
RCH	:	Reproductive and Child Health
RCI	:	Rehabilitation Council of India
RoP	:	Record of Proceedings
RPDA	:	Rights of Persons with Disabilities Act
RSUQ	:	Rajya Sabha Unstarred Question
SADD	:	Sex, Age and Disability Disaggregation
SBM	:	Swachh Bharat Mission
SDG	:	Sustainable Development Goal
SHG	:	Self Help Group
SIDPA	:	Scheme for Implementation of the Rights of Persons with Disabilities Act
SJED	:	Social Justice and Empowerment Department
SNCU	:	Special Newborn Care Unit
SSA	:	Samagra Shiksha Abhiyan
THR	:	Take-home Ration
UDID	:	Unique Disability Identity
UDISE	:	Unified District Information System for Education
UNCRC	:	United Nations Convention on the Rights of the Child
UNCRPD	:	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	:	United Nations Children's Fund
UT	:	Union Territory
WASH	:	Water, Sanitation and Hygiene
WCD	:	Women and Child Development
WHO	:	World Health Organization

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Children with disabilities in Madhya Pradesh

As per census (2011) there are nearly 4.63 lakh children with disabilities living in Madhya Pradesh[1].

At only 1.46% of child population, it is highly undercounted as an earlier report by World Bank (2007) showed that people with disabilities comprise between 4 and 8 percent of the population in India[2].

Children with disabilities account for 29.86% of total people with disabilities in the state.

It is important to note that the proportion of females among children with disabilities is reported as only 44% as against the overall proportion of 48%.

A high 71% of the children reside in rural areas, while only 29% in urban areas.

A high proportion (59%) of children with disabilities is reported in the 10 to 19 years age-group; followed by 25% in the age group 5 to 9 years and 16% below 5 years.

Hearing impairment and locomotive disability affects the largest share of these children (18% each); followed by visual impairments (17%), intellectual disability (9%) and speech impairment (6%).

As per the national Unique Disability ID (UDID) portal (2025) around 83,258 of have UDID cards. This includes around 50,371 boys and 32,867 girls.

Introduction

Children with disabilities form a large proportion (29.86%) of the total population of people with disabilities (PwDs) in Madhya Pradesh. It is most crucial that the specific needs of PwDs is met at a younger age- in terms of diagnostics, certification, early intervention, etc. Unfortunately, children with disabilities, more often than not, fall between the cracks. They are neither a priority target group under programmes for children, nor are they a priority target group under programmes targeting PwDs. This leads to a lack of data and research on children with disabilities-a major impediment for evidence-based decision making.

UNICEF (Bhopal), thus proposed to undertake a diagnostic review of the outreach of health, nutrition, and education programmes to children with disabilities in Madhya Pradesh.

The review was undertaken with the following objectives in mind:

- ⇨ To highlight the status and concerns for enabling health and nutrition outcomes for children with disabilities;
- ⇨ To map the specific provisions/ entitlements for children with disabilities under current legal and policy provisions;
- ⇨ To identify programmes and schemes which align with fulfilling the legislative and policy commitments;
- ⇨ To assess the coverage of children with disabilities within key programmes and schemes;

[1] Estimates based on projected population for 2021 and proportion of children with disabilities among total child population in census 2011 comes to around 4.55 lakhs.
[2] As per the World Health Organization (WHO, 2011) globally the proportion of world population with a disability is 15%.

- ⇨ To mark the gaps in coverage, and outline implementation bottlenecks including in budgetary allocations; and
- ⇨ To provide a set of short-term and long-term action areas for improving the coverage and quality of government services.

While acknowledging the importance of preventive measures, community-based rehabilitation (CBR) and civil society efforts; given the resource constraints the diagnostics focused only on rehabilitation measures and core government services for children and PwDs.

The diagnostics is based mostly on secondary literature review using global and nationally available data. State level data has been limited to those provided by state departments and publicly available sources mainly parliament questions and national government reports. Key informant interviews and discussions were held with government officials and service providers including frontline workers, NGO representatives, and parents of children with disabilities. Field visits were conducted in Raisen and Bhopal districts for understanding the grassroot reality.

Right to health, nutrition and therapeutic services

All children, including those with disabilities, have the right to health and medical care. The United Nations Convention on the Rights of the Child (UNCRC article 24) and the Convention on the Rights of Persons with Disabilities (UNCRPD article 25), both protect the right of children with disabilities to access health care and live healthy lives.

Article 39 (f) of the Constitution of India also provides that the state shall direct its policy towards ensuring "that children are given opportunities and facilities to develop in a healthy manner and in conditions of freedom and dignity and that childhood and youth are protected against exploitation and against moral and material abandonment."

The Rights of Persons with Disabilities Act (RPDA), 2016 also specifies the need for government and the local authorities to take measures to ensure that children with disabilities enjoy their rights equally with others; to ensure that all children with disabilities have right on an equal basis to freely express their views on all matters affecting them and to provide them appropriate support keeping in view their age and disability. The Act also recognises the need for governments to screen all the children at least once in a year for the purpose of identifying "at-risk" cases.

The National Policy of Persons with Disabilities, 2006 endorses the right to care, protection and security for children with disabilities, along with inclusion and effective access to health, vocational along with specialized rehabilitation services to children with disabilities. The National Policy for Children (2013) mandates that all children have equal rights, and no child shall be discriminated against, on grounds of disability. The National Plan of Action for Children (2016) also mandates the need to focus on children with disabilities, along with recognising the need to have targets related to the percentage of disabled children covered under any government benefit/scheme.

The Sustainable Development Goal (SDG) 3 specifically seeks to ensure healthy lives and promote well-being at all ages, including the expansion of health and vaccination coverage and putting an end to preventable deaths in children under 5. SDG 2.2 targets to end all forms of malnutrition by 2023, and by 2025, achieving, the internationally agreed targets on stunting and wasting in children under 5 years of age. It also aims to address the nutritional needs of adolescent girls, pregnant and lactating women and older persons.

Indications from available reports (UNICEF, 2022), however, shows that children with disabilities might not fare well in terms of access to health care access and in fact report poorer health and nutrition outcomes. This is in spite of the well-known fact, that they generally have a greater need for healthcare and nutrition support systems.

Health and nutrition concerns of children with disabilities

Children with disabilities face poorer health outcomes. A recent international cross-sectional study showed that in almost half the 30 countries studied, children with disabilities had at least five times greater odds of reporting having been seriously ill in the last year than children without disabilities (H. Kuper, et al., 2014). The study also points out to the fact that children with disabilities are more likely to report serious illnesses.

Children with disabilities are also more likely to report episodes of diarrhoea, acute respiratory symptoms and fever than children without disabilities (UNICEF, 2021). The report adds an example showing that 22% of children with more than one functional difficulty reported an episode of diarrhoea in the past two weeks, compared with 9% of children without functional difficulties. It also shows that children with disabilities are 53% more likely to have symptoms of acute respiratory infection (ARI).

Small-scale research studies from India (Agarwal, Utkarsha, and Sumathi Muralidha, 2016) also highlights that children and young persons with disabilities have a similar or increased risk of contracting sexually transmitted infections compared with those without. The study also points to girls with disabilities experiencing higher infection rates than boys with disabilities.

Malnutrition levels are higher than other children. Children with disabilities are 42% more likely to be underweight[3], 25% more likely to be wasted and 34% more likely to be stunted[4] (UNICEF, 2021). Malnutrition in children with disabilities can be attributed to many factors, including a) physical problems in feeding; b) suboptimal feeding practices due to lack of knowledge or specific skills among caregivers; and c) attitudinal, social or cultural causes such as the exclusion or neglect of children with disabilities in feeding practices, socially or in the home (Groce, Nora E., et al, 2013). Children with disabilities also often miss out on the benefits from school-based nutrition or food security programmes as they are less likely to attend school than their peers without disabilities (Groce, Nora, Eleanor Challenger, and Marko Kerac, 2013). Children with disabilities living in child care institutions (CCIs) and orphanages are even more vulnerable, as their nutrition tends to suffer due to inadequate staffing and discriminatory practices and where nutrition programmes are often overlooked (Groce, Nora E., et al, 2013).

Additional therapeutic support is required. Children with disabilities also need timely identification and additional support in their early years to allow them to maximize their development and functioning (Kuper Hannah, and Phyllis Heydt, 2019). Further they often require rehabilitation therapies that can optimize functioning and prevent secondary complications. These are much beneficial for many such children with far-reaching implications for participation in education, community activities and, in later years, work.

Access to health care is however limited. A recent systematic review, including 127 studies from low- and middle-income countries, shows that people with disabilities tend to have higher need for general healthcare services, but poorer coverage, more healthcare expenses, and low access to specialist healthcare services, such as rehabilitation and assistive technologies (T. Bright, S. Wallace, H. Kuper, 2018). The same has also been reported in India, where some older NSS data suggests that those disabled from birth, in rural areas and women are less likely to seek health care (World Bank, 2007).

The situation of children with disabilities is not expected to be very different. UNICEF (2022) also quotes data showing that children with disabilities often do not receive basic treatment for common childhood illnesses, which can become a risk to their lives if not prevented or treated. There is often a

[3] 28 per cent, compared with 19 per cent of children without disabilities.
[4] 43 per cent, compared with 30 per cent of children without disabilities.

significant delay in seeking medical care especially for children with intellectual and developmental disorders (UNICEF, 2021).

Most likely to miss out on vaccinations. Immunization is key to protecting children from vaccine preventable diseases. Children with disabilities are at greater risk of missing out on vaccinations than their peers without disabilities (UNICEF and LCDIDC, nd). Even in countries where overall immunization rates have significantly increased, children with disabilities are overrepresented among the group not benefiting from immunization programmes (ibid). Ensuring coverage of children with disabilities in immunization programmes is crucial not only to protect children from vaccine-preventable diseases, but also linked intrinsically with other life support measures like vitamin A supplementation, iron supplementation, deworming medicine for worms' infestation, etc.

Many do not have the assistive technology that they need. Assistive technology (AT) – including wheelchairs, prosthetics, glasses, hearing aids and screen-reading software – is instrumental for the development and participation of children with disabilities, by enabling their communication, mobility and self-care. Technology also allows each child to explore the world of family relationships, friendships, education, play and household tasks, enhancing their quality of life and that of their families. For the vast majority of children with disabilities, however, inadequate access to assistive technology, or none at all, excludes them from education, health and social services, resulting in lifelong consequences for their participation in civic life and employment (Borg, Johan, et al., 2015). In fact, it is estimated that globally over one billion people need some form of assistive technology, yet 90% do not access to the same (Global Need for AT).

There are multiple barriers in accessing care facilities. Children with disabilities face significant barriers in accessing health care, including stigma, lack of financial resources, inaccessible facilities, lack of transportation, inability to communicate, an absence of privacy at care facilities and inadequately trained health-care staff. For example, they may be excluded from immunization programmes due to them being incorrectly assumed not to be at risk, being hidden by stigma, and being affected by a lack of accessibility at vaccination facilities and health centres (UNICEF and LCDIDC, nd). Some studies in Africa also note that delays in care-seeking by parents of children with intellectual and developmental disabilities have also been found to be associated with challenges in controlling the child's behaviour in public as well as accessing health facilities that are trusted by parents (Lamptey, De-Lawrence, 2019).

In Indian context, **high out of pocket expenditure (OOPE)** for disability-related healthcare[5] is also a big barrier. A person with disability incurs an average OOPE of Rs 2,477/- per month (Arunima Rajan, 2024). On an average, this is 20.32% of a household's monthly consumption- solely to manage life with disabilities for one of its members. Such a significant portion of household consumption being diverted to healthcare can potentially push families into debilitating poverty.

Other studies (World Bank, 2007) further show that while higher expenditures are a barrier, **limited physical accessibility of health systems and the attitudes of health care providers** also restrict access to health care services by people with disabilities. Key informant interviews and field visits undertaken as part of this study, further revealed the following barriers:

- **Lack of training among frontline health care workers** like ASHAs, Anganwadi workers, and Special Newborn Care Unit (SNCU) staff who can be crucial for early detection and intervention. The presence of this huge frontline staff specifically working for children is potentially a great opportunity for reaching out to children with disabilities, provided their capacities are adequately enhanced.
- **Limited medical care being available at local level**. For example, in Raisen, it was shared that even when the parents take children to the local district hospital, they are often referred to Bhopal

[5] Which includes, and is related to the disability itself or other health issues too, which may not be stemming from the disability per say.

for treatment by a private service provider. The district hospital in fact provides only limited services to children with disabilities, with focus primarily on disability assessment and certification. Additionally, a few cochlear implants are undertaken with support from Rashtriya Bal Swasthya Karyakram (RBSK) team. Even eye surgeries are not undertaken, although the hospital has the full required quota of specialist on board- orthopaedic surgeon, eye surgeon, ear, nose, and throat (ENT) specialist and mental health specialist.

- **Available services are not accessible**. For example, in the district hospital visited at Raisen, the physiotherapy centre was on the second floor without any lift facilities. This makes it less usable for people with disabilities. The overcrowded hospital with lack of private and quiet spaces also makes it less accessible for children with intellectual disabilities. A child with autism, for instance, needs a quiet space for their treatment, which is often not available at district hospitals.
- **Rehabilitation services are limited and not accessible in remote locations**. There are very few private rehabilitation service providers available outside major cities like Bhopal and Indore. The government run District Disability Rehabilitation Centres (DDRC) are also available only at district headquarter. With no transport facilities available, people from rural areas cannot access the services. Furthermore, even in the urban areas, they are often located in remote locations without proper infrastructure facilities. There is very limited information on DDRC and type of services provided therein. Also, the infrastructure, services and equipments available with respect to the specific needs of children with disability is inadequate.
- There is also an **indifference among parents of children with disabilities**, who are often content with cash transfers and not really worried about health care and rehabilitation services for their children.
- However, even when parents take initiative and work to get treatment for their children, there is **limited awareness and knowledge** on what to do and where to avail the service is low.
- Disability is largely **absent from the medical curriculum**, so healthcare professionals are often ill-prepared to treat patients with disabilities effectively**.**
- **Apathy of medical practitioners**, also often results in children not being recommended for clear tests and therapy rather being forced to continue treatment to no avail. It is important to strengthen empathy and responsiveness towards children with disabilities among medical practitioners with a more patient centred and rehabilitation (rather than treatment) based approach.

Inadequacy of water and sanitation services add to the impediments. Children with disabilities are 12% less likely to have improved drinking water sources in their households, compared with children without disabilities, and 8% less likely to have improved sanitation facilities in their households (UNICEF, 2021). Even when households have improved sanitation facilities, these are often not accessible or usable by individuals with disabilities. One substantial challenge facing children with disabilities is the location of toilets or latrines and whether they are on the premises or at a distance and shared with other households. Other barriers, such as structural issues in the design or the inability to use sanitation facilities with independence and dignity, further contribute to inaccessibility regardless of whether the facility is on the premises or not. A lack of accessible sanitation facilities can result in children with disabilities being dependent on others' help to use them. This can erode children's self-esteem and cause them to be perceived as a burden (Groce et al, 2019). Challenges in accessing sanitation services can also limit a child's attendance and participation in school, resulting in poor educational outcomes (UNICEF, 2021).

Access to menstrual hygiene is an even greater challenge. Lack of basic and private water, sanitation and hygiene (WASH) services that are accessible to adolescent girls with disabilities are a major barrier to adequate management of menstrual hygiene. In contexts of social and economic vulnerability, this barrier is often compounded by the struggle to access menstrual hygiene products. However, even when such products and services are available, girls with disabilities can still have problems using them, either physically or through lack of understanding of how to use them

(Altundağ, Sebahat, and Nazan Çakirer Çalbayram, 2016). When girls with disabilities are unable to manage menstrual hygiene, they face increased risks of not participating in everyday activities, more so on missing out on school, feeling ashamed and socially isolated.

Children with disabilities are also more vulnerable to sexual violence. Children with disabilities, particularly girls with disabilities, are also at increased risk of sexual violence, which further increases their risk to unwanted pregnancies and sexually transmitted infections (Groce, Nora, et al., 2013). Furthermore, adolescents with disabilities, without proper knowledge may also engage in risky sexual behaviours, putting them at further risk. However, global reports (UNICEF, 2022) show they are often excluded from sexual and reproductive health services. In India, where challenges already exist for all adolescents to access these services, the additional barriers faced by children puts them at further risk increasing their vulnerability.

Legislations and policies impacting health of children with disabilities

National Health Policy

There is no universal health care Act in India. In 2017, the GoI adopted a new National Health Policy. Building on the National Health Policy of 1983 and the National Health Policy of 2002; the new policy envisages as its goal the attainment of the highest possible level of health and wellbeing for everyone across all ages, with a specific focus on minimizing disparity on account of disability and to progressively achieve Universal Health Coverage. The policy has specific targets for children in terms of reducing neo-natal, infant and child mortality rates; achieving more than 90% full immunization rates; and reduction of 40% in prevalence of stunting of under-five children. While there are no specific targets for persons with disabilities, the policy recognises the provisions of the mental health policy, while supplementing it with additional actions related to creating a network of community members to provide psycho-social support and leveraging digital technology to reach unserved areas. Additionally, the policy has two important considerations specifically relevant for children with disabilities:

- An expansion of scope of interventions to include early detection and response to early childhood development delays and disability, adolescent and sexual health education.
- Change from very selective to comprehensive primary health care package which includes palliative care and rehabilitative care services.

Rehabilitation Council of India (RCI) Act

The Rehabilitation Council of India (RCI) Act of 1992 was passed to regulate services for people with disabilities. The Act was amended by Parliament in 2000 to make it broader-based. The Act aimed to:

- Standardize training and syllabi for rehabilitation professionals;
- Monitor and regulate services for people with disabilities;
- Promote research in rehabilitation, special education, and prevention;
- Maintain a central register of qualified rehabilitation professionals; and
- Take punitive action against unqualified rehabilitation professionals.

The Act also established a central register of qualified rehabilitation professionals. The Rehabilitation Council of India has been set up as a statutory body under the Act and its specific role is to develop, standardize and regulate training programmes/ courses at various levels in the field of rehabilitation and special education.

Mental Healthcare Act (MHCA)

For persons with intellectual disabilities, the Mental Healthcare Act (MHCA) was enacted by GoI in 2017. Compared to its predecessor the Mental Health Act of 1987, this act is purported to be more patient centric and rights based. The MHCA mandates all persons aged less than 18 years to be treated

as minors. Other specific MHCA mandates for children with disabilities (Sharma E and Kommu JVS, 2019) include:

- Only nominated representative (NR) is authorized to make advance directives for mental healthcare of minors. By default, parents/legal guardians are NR for minors[6].
- Children under the age of 3 years cannot be separated from their mother while getting treatment in a mental healthcare institution unless there is any risk to the baby from the mother's ill health[7].
- Inpatient treatment for minors requires the recommendation of two MHPs or one MHP and one medical professional. Consent only of the NR is needed.
- Separate, developmentally appropriate facilities are to be set up for inpatient treatment of minors.
- Minors are to be admitted along with NR. Only a female attendant must accompany minor girls.
- All admissions of minors have to be reported to the concerned Mental health review boards (MHRB)[8] within 3 days.
- Electroconvulsive therapy (ECT) can be used in minors only with prior permission of the MHRB and with the consent of the NR.

The MHCA improves on its predecessors in terms of greater clarity on a range of issues surrounding the mental health care of children and adolescents. It is more elaborate on inpatient admission procedures and treatments such as the use of electroconvulsive therapy. There is a clearly stated role of NRs. Another positive move is the decriminalization of suicidal behaviours. This is especially relevant in the case of adolescents who have high rates of self-harm and suicidal behaviours, which indicate the presence of serious psychological distress, that requires urgent medical and/or psychiatric intervention. Till recently, the criminal perspective and legal consequences of such behaviour was a barrier to help-seeking.

However, the MHCA is limited in its scope of consideration about the rights of the child/adolescent to be an active participant in his/her mental health care. Furthermore, provisions for admissions and treatments, for example, the need for two professionals to independently opine on the need for admission, are likely to increase regulatory control. Most importantly though, is the challenge in implementation of the MHCA in the context of children with disabilities.

- The role of MHRB becomes very important in their context. However, there are challenges in setting up of the MHRB due to human and financial resource constraints at appropriate levels. For example, in Raisen, there seemed to be limited knowledge related to the status of MHRB among the district officials.
- The setting up of separate facilities for admission of minors. The minimum quality standards of these will be required to be specified by the State Authority. Given the already existing infrastructure challenges at medical facilities, it will be important to set pragmatic yet doable standards and ensure its implementation.
- Services such as promotion of mental health and preventive programmes, creating awareness about mental health and illness and reducing stigma associated with mental illness, and measures required to address the human resource requirements of mental health services through education and training, are duties of appropriate government. However, currently there does not seem to be any specific provisions being made by state governments for the same. Awareness and human resource development on mental health services are specifically required for children with intellectual disabilities.

[6] Concerned MHRB can appoint another individual as NR if the parent/legal guardian is found unsuitable. However, the concerned mental health authority, treating mental health professional, or any other person acting in the child's best interest must bring this to the notice of the MHRB.

[7] Even if the baby has to be separated, the mother will have supervised access. The decision to separate the baby has to be reviewed every 15 days, and the baby should be reunited with the mother at the earliest possible. If a baby has to be separated for>30 days, the concerned mental health authority must be informed.

[8] The MHRBs are chaired by a District Judge and members include one representative of the District Collector, one psychiatrist, one medical practitioner and two representatives of persons with mental illness/caregivers/ NGOs working in the field of mental health.

An earmarked budget by the Department of Health and Family Welfare, is required for MHCA's implementation, including setting up of MHRB, a focused work area, better coordination with agencies responsible for setting up of separate developmentally appropriate facilities for inpatient treatment of minors, provision of mental health and preventive programmes, etc. is vital.

National Mental Health Policy

The GoI had also adopted the National Mental Health Policy in 2014. The policy highlights cross-cutting issues like stigma, right-based approach, vulnerable populations, adequate funding, support for families, intersectoral coordination, institutional care, promotion of mental health, and research. The key strategic areas for intervention include:

- Effective governance and delivery mechanisms for mental health;
- Promotion of mental health at the level of anganwadi centre, schools, workplace, etc.;
- Prevention of mental illness and reduction of suicide and suicide attempts;
- Universal access of mental health services [family-centric services, increasing the availability of the community-based rehabilitation (CBR) services, assisted living services, etc.];
- Improved availability of the trained mental health human resources in the community; community participation for the mental health and development; and
- Research on mental health and allied disciplines.

The policy also outlines important aspects of justice for the vulnerable groups like homeless, orphaned children, children in conflict with the law, etc. However, this requires a concerted effort from different stakeholders (legal experts, social-welfare organizations, educationists, etc.) who might, at times, have different mandates (Gupta S and Sagar R, 2021). For instance, mental health needs of the children in conflict with the law can only be achieved when the legal system and civil society, work in collaboration with the social-welfare agencies and mental health professionals (MHPs) for improving the lives of children in conflict with law and preventing recidivism (ibid). Else without acknowledging the bio-psycho-social model of mental illness (and associated behaviours, including legal offenses), they may end up endorse punitive measures for such children (ibid).

Further, although the policy is provisioned for community rehabilitation, its ground-level implementation is still abysmally low. This is attributable to poor mental health resources; sub-optimal linkage among mental health services, allied health facilities, and social welfare schemes; and lack of involvement of the community leaders, non-governmental organizations (NGOs), and private sector (ibid). There is an urgent need to infuse more financial and human resources that can be utilized in organizing awareness campaigns; mobilize community resources by training the community health workers, laypersons, and community members in rehabilitative services; provide rehabilitative services at multiple levels (daycare and residential care, routine psychosocial activities, outreach activities, livelihood activities, etc.); and set up integrated CBR programs by involving various stakeholders.

Programmes and schemes impacting health access, nutrition and rehabilitative services

The programmes and schemes impacting health care access and rehabilitative services for children with disabilities can be divided into two parts:

A. General programmes which aim for universal health care including immunization; access to primary, secondary and tertiary medical services; nutrition services; and
B. Targeted programmes including early detection and prevention, assistive technology provision, rehabilitation therapies and national programs for blindness and visual impairment, deafness and mental health.

General programmes

National Health Mission (NHM)

What began as national rural health mission in 2005, has since 2017 been implemented as the National Health Mission (NHM) with inclusion another sub-mission on urban health. Reproductive and child health (RCH) services form an integral part of NHM, along with various national programmes for communicable and non-communicable diseases [9] . Interventions under the child health programme include newborn health; nutrition; pneumonia and diarrhoea; birth defects, developmental delays and deficiencies; and immunization. There is a target of universal access and coverage across all these interventions, which mean children with disabilities are also entitled to the benefits of all the above programmes.

To eliminate sickle cell disease, Sickle Cell Anaemia Elimination Mission has been launched by Hon'ble Prime Minister from Madhya Pradesh on 1st July, 2023. The mission has a target of screening of 7 crore people till year 2025-26 in affected 278 districts of tribal areas and provision of counselling through collaborative efforts of central ministries and state governments. Under the national Sickle Cell Anaemia Elimination Mission, a total of 261.38 lakh persons in 17 identified states had been screened and a total of 104.51 lakh sickle cell cards distributed till March 2024. **Specific data for the state of Madhya Pradesh and on children with disabilities is not available.**

Unfortunately, except as part of identification of birth defects and developmental delays, referral and treatment services as part of the Rashtriya Bal Swasthya Karyakram (RBSK) (discussed in detail later in the chapter), none of the above interventions have specific actions or monitoring of data on coverage of children with disabilities. **Even the national family health survey (NFHS), which collects data on RCH status does not provide information on status of children with disabilities, separately**. **Sample Registration System (SRS) which provides data on mortality rates also lacks disaggregated data based on children with disability**.

The children are assumed to be covered under the veil of universalization. However, this is still a distant dream, considering that full immunization coverage in Madhya Pradesh was only 93.19% in 2023-24 (PIB, 2024). Global evidence suggests that **children with disabilities are most likely to be those left behind in immunization, nutrition, pneumonia and diarrhoea treatment programmes**. Deliberations with the community and key informants also revealed gaps in sensitization and training of frontline workers- SNCU staff, Asha and anganwadi workers on early detention and aftercare of children with disabilities. **The parents of children with disabilities also seemed to have low awareness on the full immunization schedule required for their children or an indifference towards the same**. It is important to understand the status of coverage of children with disabilities for immunization, nutrition supplements and pneumonia and diarrhoea treatment programmes. The Department of Health and Family Welfare (GoMP) needs to undertake a specific study towards understanding the same.

Another key component is the setting up of **Ayushman Arogya Mandirs (AAMs)** [10] to provide comprehensive primary health care. It is also envisaged to incrementally add primary healthcare services for mental health, ENT, ophthalmology, palliative health care, etc, which will have specific implications for people with disabilities. Presently, specific operational guidelines and training manuals to enhance the capacity of medical officers, community health officers (CHOs) and community health workers (CHWs) have been developed for the wide-scale implementation of the mental health service package (Bhushan Girase, 2022).

[9] This includes programmes for blindness and visual impairment, deafness, and mental health discussed later in the chapter.
[10] Erstwhile Ayushman Bharat Health and Wellness Centre

Another component of NHM is the **Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY)**. This is a health insurance scheme in India which provides health cover of Rs. 5 lakh per family per year for secondary and tertiary care hospitalization. All disabled individuals who meet the eligibility criteria are entitled to benefits under the scheme. Specifically, it includes medical and surgical packages for mental and neural disabilities, spinal injuries, brain injuries, and muscular dystrophies; covers surgical procedures like orthopaedics, oral and maxillofacial surgery, and polytrauma; as well as cochlear implant surgery and surgery for spine and foot deformation. However, the eligibility criteria often restrict people with disabilities to avail benefits of the scheme. This can have a higher impact on children from lower middle-class families, as their parents might not be able to avail private health insurance as well.

> The National Disability Network (NDN), a cohort of organisations and federations of persons with disabilities, has approached the Central government seeking inclusion of people with disabilities without any income as well as age criteria in the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY) health insurance scheme.

Data on coverage of children with disabilities under the current scheme is not available. However, given the low level of awareness (as was also observed during the field visits) it is highly unlikely that there would be adequate coverage among the eligible beneficiaries. The state needs to focus on targeted awareness and drives for enrolment of children with disabilities under the scheme. This could be further strengthened by addition of a top-up incentive to beneficiary facilitation agencies (BFA) to undertake screening and facilitate enrolment of such children and attend to the needs of beneficiaries, especially timely submission of treatment claims.

Pradhan Mantri Ayushman Bharat Health Infrastructure Mission (PM-ABHIM)

Launched in 2021, this is the largest pan India scheme for strengthening healthcare infrastructure across the country. Much of its funding is targeted towards building primary health care centres (AAM), public health units, critical care hospital blocks, etc. An important aspect of this would be ensuring that all the new infrastructure created is accessible. Already the Ministry of Health and Family Welfare, vide notification number F.No. T.21017/20/2021-NCD.I (NPPCD)/Part., dated the 4th May, 2023" has issued "Accessibility Standards for Health Care". The Department of Empowerment of Persons with Disabilities (DoEPwD) has also issued a gazette notification dated 9th August,2023, recognising the same as a mandate under the RPDA (2016). However, action on the ground seems to be limited.

> The DoEPwD (GoI) has been implementing the Scheme for Implementation of the Rights of Persons with Disabilities Act, 2016 (SIPDA) for providing financial assistance for undertaking various activities relating to rehabilitation and provision of barrier-free access. From 2014-15 to 2024-25 (as on 31.05.2024), Rs. 167.45 crores have been released for retrofitting 10019 buildings of state/UT govt, including autonomous organization/NIs and statutory bodies. However, there are hardly any hospitals or medical centres which have been retrofitted/upgraded under the scheme.

Visits to district hospitals in Madhya Pradesh reveal that most do not adhere to the accessibility standards. Ramps and handrails, have been placed at a few places, however, the overall sense of accessibility and sensitivity is missing. For example, in Raisen, the physiotherapy centre itself was on the second floor with no ramp access. Furthermore, discussions with state officials have revealed that district hospitals in the state have generally not been audited for accessibility. The Department of Social Justice and Empowerment (SJED), GoMP, needs to undertake accessibility audits for all district hospitals in the state.

Additionally, PM-ABHIM targets to build an information technology (IT) enabled disease surveillance system by developing a network of surveillance laboratories at block, district, regional and national levels. It will important to ensure that the systems thus created within PM-ABHIM ensure sex, age and disability disaggregation (SADD). The state of Madhya Pradesh, which already has an integrated platform "Samagra" for targeted social protection services, can pilot a model for collection of health

information related to children with disabilities. The pilot can serve as model for integration within the national system.

Health Insurance for disabled

The Department of Financial Services had informed the parliament that the Insurance Regulatory and Development Authority of India (IRDAI), vide circular Ref no. IRDAI /HLT/CIR/MISC/58/2/2023 dated 27.02.2023, have mandated insurers to offer products that provide health insurance coverage to persons suffering from disabilities (Loksabha question, 2023). The model product specified vide above referred circular provides coverage to 21 disabilities defined under RPDA, 2016. Accordingly, all general and health insurers have launched their respective products offering coverage to persons with disabilities in line with the circular (ibid). Notwithstanding the guidelines, however, for coverage, the policies available are still limited (Arunima Rajan, 2024). Given that children in India do not have separate health insurance coverage but are generally included in family coverage, higher insurance premiums will have a more negative impact on their coverage.

> "*Most products offer only a mere ₹5 lakh in hospitalisation cover, but they have high premiums. Apart from this, even if there is a policy, awareness about it remains low, but more importantly affordability becomes a huge issue*." Mr. Ali, Executive Director of the National Centre for Promotion of Employment for Disabled People (NCPEDP).

Poshan Abhiyan

Building on the Integrated Child Development Services (ICDS), the Poshan Abhiyan was launched in 2018, with the vision to ensure attainment of malnutrition free India by 2022. The objective of Poshan Abhiyaan is to reduce stunting by improving the utilization and quality of key anganwadi services. It's aim to ensure holistic development and adequate nutrition for pregnant women, mothers and children.

In November 2023, the **Anganwadi Protocol for Divyang Children**, was launched by the Ministry of Women and Child Development (MWCD), GoI. The protocol embodies a social model for inclusive care under the Poshan Abhiyan, with a step-by-step approach:

Step 1: Screening for early disability signs

Step 2: Inclusion in community events and empowering families

Step 3: Referral support via ASHA/ANM and Rashtriya Bal Swasthya Karyakram (RBSK) teams.

It is expected that through the Divyang protocol, district administration will be guided in addressing special needs for education and nutrition, **providing Swavlamban Cards for the empowerment of children with disabilities** and their families. The Ministry also proposes that the developmental milestones of the children will be tracked on the Poshan tracker and the data will further support convergence between relevant ministries. Additionally, the ministry has also allocated Rs. 300 crores for training, and capacity building of Anganwadi Workers for identification, referral and inclusion of children with disabilities. MWCD, however, recognises that the support of DoEPwD will be crucial in enabling the capacity building programme.

The state of Madhya Pradesh has been diligently thriving to address the issues of malnutrition through implementation of Poshan Abhiyan and Saksham Anganwadi 2.0. Data from National Family Health Survey (NFHS- 4, 2015-16; NFHS-5, 2019-20) shows a visible improvement in stunting (from 42% to 35.7%), wasting (from 25.8% to 18.9%) and underweight (42.8% to 33%) levels among children below 5 years of age.

Notwithstanding the progress made by the state on reducing malnutrition though there is no focus on children with disabilities. **The state nutrition policy (2020-2030) does not mention anything**

about the nutritional status and specific needs of children with disabilities. Field visit as part of the study, however revealed that:

- The Anganwadi worker are generally well aware of the children with disabilities in the neighbourhood. Although she might have not received any formal training on issues related to them.
- Children with disabilities are not kept full time at the anganwadi centre, but parents are aware of the services provided especially weighing and take-home ration (THR).
- **Children with disabilities seem to be covered under nutrition schemes for THR and weight monitoring**. Although they are not present at the anganwadi centre, parents come in at times for weighing and take the THR every week. The **coverage of children with disabilities under the programme is, however, completely untracked**, making it difficult to undertake any analysis. Furthermore, status on how much of the THR is actually consumed by the child is not known.
- There are no targeted activities like additional rations for children with disabilities or specific toys or learning devices available at anganwadi centre. In fact, running in small areas, it is difficult for the centre to retain and care for children with disabilities.
- Most anganwadi workers (even the local supervisor in this case) are not aware of the activities of District Disability Rehabilitation Centre (DDRC) and other provisions available for children with disabilities.

Swachh Bharat Abhiyan

Launched in 2014; to promote a clean India, the Swachh Bharat Mission (SBM) has a strong thrust on equity, and gives attention to the special needs of people with disabilities especially in rural areas. The demand for toilets is assessed by the concerned state govts/UTs. Although updated and Madhya Pradesh specific data is not available, data from 2019 (LSUQ No 329) shows that nationally 12,12,950 accessible toilets have been constructed under SBM(Gramin) in the year 2017-18 to 2019-20; and 6,562 accessible toilets have been constructed under SBM (Urban), up to March, 2018.

Udita Yojana

Started on November 2016, the Udita Yojana is a state scheme of the GoMP run by the Women and Child Development (WCD) Department. The aim of this scheme is to improve the health and nutrition of adolescent girls and to eliminate their problems. All teenage girls and women between 18 and 49 years can avail the benefits of this scheme. Under this scheme, Udita corners have been created in Anganwadi centres; wherein adolescent girls are informed about menstrual health and provided sanitary napkins. Again, data on coverage of girls with disabilities under the scheme is not available. Further, key informant interviews reveal that it is an open scheme and there is currently no focussed targeting of girls with disabilities under the same. The WCD Department need to provide training to Anganwadi workers on the specific menstrual hygiene needs of girls with disabilities, especially the handling of sanitary napkins.

Targeted programmes

Rashtriya Bal Swasthya Karyakram (RBSK)

Launched under NHM, the Rashtriya Bal Swasthya Karyakram (RBSK) involves screening of children from birth to 18 years of age for 4 Ds- Defects at birth, Diseases, Deficiencies and **Development delays**[11], spanning 32 common health conditions for early detection and free treatment and management, including surgeries at tertiary level. The technical and financial support is provided to the States/UTs under the NHM for infrastructure, essential equipment and required human resources at District Early Intervention Centres (DEIC) including capacity building for comprehensive management of selected health conditions.

[11] Children with disabilities would be mostly falling under the category of development delays

The RBSK has a high focus on screening of children. To facilitate this, there is expected to be a strong convergence between the following departments:

- Health and Family Welfare:
  - For screening of newborn for birth defects in health facilities by the doctors at health facilities and during the home visit by ASHA (peripheral health worker).
  - For screening of children in other age groups through camps and mobile health teams (MHTs)
- Women and Child Development: For screening children the age group 0 – 6 years enrolled at Anganwadi centres; and
- Education Department: For screening children above 6 years enrolled in Government and Government aided schools.

It is interesting to review the status on screening of children in the state of Madhya Pradesh. As per available data, in the last decade between FY 2013-14 to FY 2023-24; around 996.78 lakh children were screened as part of RBSK (PIB, 2023; and DHFW GoMP, 2023-23). It is surprising to note that the number of children screened has declined over the years in spite of increased visits to anganwadi centres and schools (table 1).

Table 1: Screening and identification of children with development delays in MP in last three years

Details	2021-22[1]	2022-23[1]	2023-24[2]
Number of anganwadi centres visited	48,004	57,524	89,277
Number of schools visited	52,014	62,318	70,409
Number of children screened (in lakhs)	787.15	140.73	139.14
Number of children identified with birth defects (excluding congenital heart disease)[3]	5530	NA	NA
Number of children identified with development delays (in lakhs)	1.71	3.31	0.74

Source: 1. Data received from Department of Health and Family Welfare (DHFW), GoMP; 2. Child health factsheet DHFW, 2023-24. 3. Authors calculation based on DHFW (GoMP), 2020-21

Screening needs to be optimized. The department reports a high screening rate of 83.80%, against a screening target for MHTs of 166.14 lakhs. However, as per population projections for Madhya Pradesh, in 2020, there were 311. 86 lakh children in the age group 0 to 18 years. Against this population, ***the child screening rate appears to be only around 44.62%.*** It is important to optimize the screening target in line with a more accurate proportion of children with disabilities in the state.

This is important, as screening of all children is very important for early identification of children with disabilities or those "at risk". With less than 50% of the children being screened, there is a high chance of many children with disabilities being missed. This is even more likely given that the focus of MHT screening is through anganwadi centres and school visits. Given that children with disability are mostly not present at anganwadi centres and also highly likely to be out of school (or even when enrolled have a low attendance), the proportion of children with disabilities among those missed during screening would be high. It is important to explore other avenues targeted for screening of children with disabilities. The state government should explore conducting of a study on children "at risk". Further, the involvement of local bodies like gram panchayats and municipalities/municipal corporations, in the process is currently very limited. Interviews with medical officials revealed that mostly, they are involved only for the purpose of spreading awareness on the date and place of the camps to be held. The elected

A key aspect emerging during field visits and key informant interviews that children with disabilities are screened as part of UDID camps conducted. However, it needs to be noted here that these camps are mainly for getting a disability certificate targeted at children with benchmark (40% or more) disability. In case of children, the focus should move beyond only benchmark disabilities to all disabilities to ensure a better quality of life for them in future.

representatives from local bodies need to be sensitized on the issues of children with disabilities- especially the need for early screening. They can then be more pro-actively involved in the process of spreading awareness and facilitating RBSK camps at local levels to enable increased outreach. Conducting of RBSK camps for early screening can also be included as a no-cost activity as part of the gram panchayat development planning (GPDP) process.

Identification of developmental delays is lower. The lack of coverage of children with disabilities in screening is further reflected in low identification of number of children with development defects. As per the department's own standards the percentage of developmental delay has to be 10% of the of total 4D identification. These delays, if not intercepted timely, may lead to permanent disabilities. However, in 2023-24, the percentage of development delay cases was only 3.9%, pointing out towards a large number of missing children. With only 0.74 lakh identified, this not only indicates towards a huge gap of **1.16 lakh missing count of children with disabilities**, but is also much lower than the previous two years. This further indicates the need to have a focused annual identification campaign for children with disabilities.

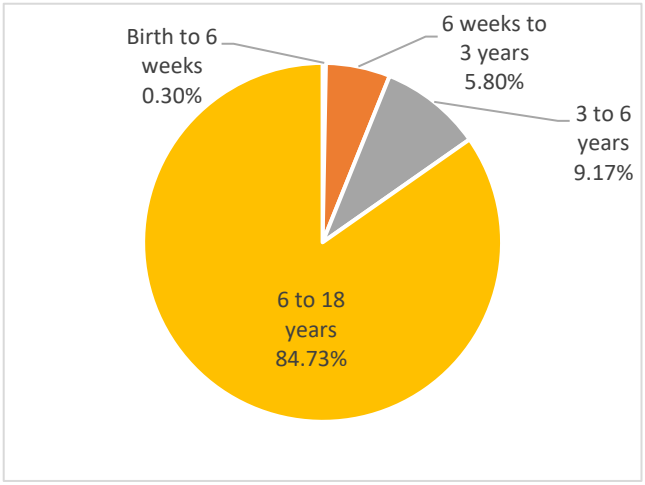

Figure 1: Children screened for various health conditions under RBSK (2020-21)

Although updated disaggregated data on identification of children is not available, if we look at select parameters between birth defects and developmental delays in 2020-21 (DHFW (GoMP)), it reflects an almost equal share of male and female children (table 2). In terms of age, the maximum proportion of children are in the age group 6 to 18 years (figure 1). Interestingly though, most of the children screened for various health conditions are classified as others (table 2).

Table 2: Children screened for various health conditions in 2020-21

Type of health condition for which the children are screened	Total			
	Male	Female	Total	Percentage
Defects at birth				
Neural tube defect	110	120	230	0.20
Down's Syndrome	261	199	460	0.40
Cleft lip & Palate	409	438	847	0.73
Club foot	1008	662	1670	1.45
Developmental dysplasia of the hip	245	203	448	0.39
Congenital cataract	252	209	461	0.40
Congenital deafness	717	606	1323	1.15
Retinopathy of prematurity	45	46	91	0.08
Microcephaly	0	0	0	0.00
Macrocephaly	0	0	0	0.00
Childhood Diseases				
Convulsive disorders	669	563	1232	1.07
Developmental Delays including disabilities				
Vision impairment	7452	9754	17206	14.91
Hearing impairment	919	1031	1950	1.69

Neuro motor impairment	1655	1267	2922	2.53
Motor delay	1137	960	2097	1.82
Cognitive delay	552	451	1003	0.87
Language delay	3022	2180	5202	4.51
Behaviour disorder (Autism)	310	283	593	0.51
Learning disorder	487	430	917	0.79
Attention deficit hyperactive disorder	117	89	206	0.18
Others	37476	39068	76544	66.33
TOTAL	**56843**	**58559**	**115402**	**100**
Percentage	**49.26**	**50.74**	**100**	
Source: DHFW, 2023-24				

Treatment/ therapeutic support. Children identified with defects and disabilities are provided rehabilitative support through physiotherapists, audiologists, dentists, psychologists, social educators, occupational therapists, etc. These services are provided free of cost, aligned with the respective National Health Programs, thus helping their families reduce OOPE incurred on the treatment. Unfortunately, **specific data on the treatment support provided to children with disabilities is not available** with the DHFW, GoMP.

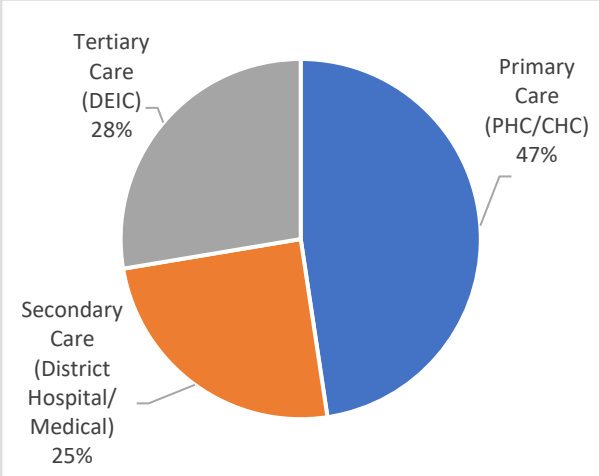

Figure 2: Level of Referrals for Children with Disabilities Identified through Screening in 2020-21 (Madhya Pradesh)

Review of publicly available older data (DHFW (GoMP), 2020-21), however, shows that of the 1.15 lakh children identified through screening, 93, 870 (81.34%) were referred. There was a slight gender gap in the referrals with the proportion of boys (82.18%) being referred higher than that of girls (80.53%). While discrepancies were observed in the age-wise data reported, the trend shows that while the referrals for children up to 6 years was high, that for children between 6 to 18 years was low (around 75.83%). Maximum referrals were at the primary level (figure 2). Gender differences were also visible here, with a higher proportion of girls (50.68%) being referred to for primary care, as against only 44.54% of boys; while the trends were reversed in case of secondary and tertiary care (figure 3).

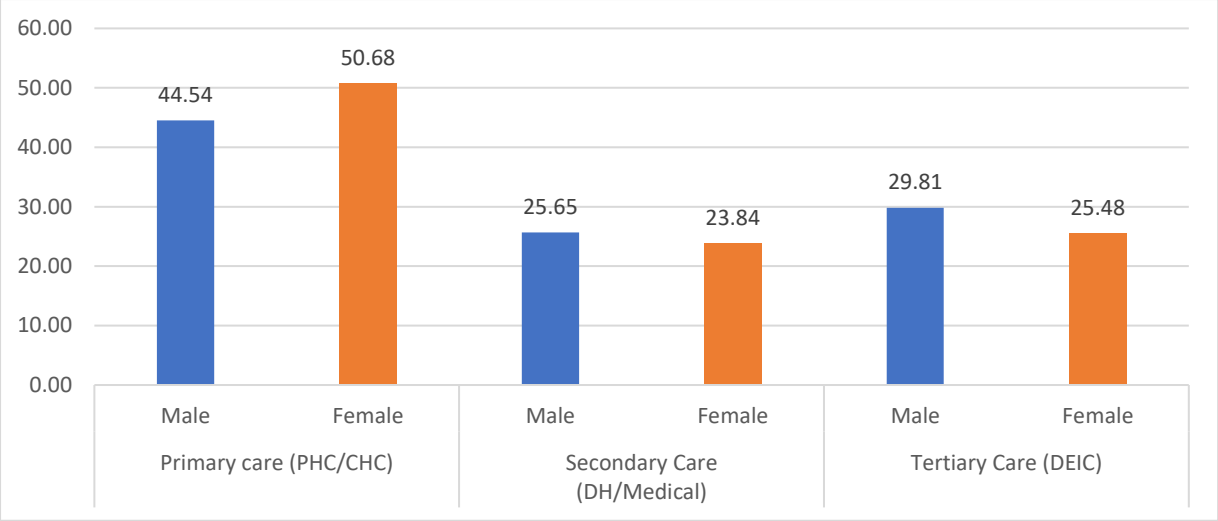

Figure 3: Percentage of male and female children identified referred a for different levels of care

Box 1: Status of DEICs formed under RBSK in Madhya Pradesh

All districts in Madhya Pradesh have DEICs established. However, there seems to be gaps in in terms of quality of infrastructure and service. A cross-sectional study to evaluate the functioning and infrastructure of DEIC, and client satisfaction Ujjain and Indore districts established under RBSK (Parmar S, et al., 2016) reveals the following:

- DEIC of Indore and Ujjain district were deficient in staff and infrastructure.
- Among all referred cases to various facility 10.24% were referred to DEIC Indore while in Ujjain 20.1% were referred to DEIC.
- Among all the referred cases only 5.2% and 6.01% reached the DEIC Indore and Ujjain respectively.
- 76.92% beneficiaries were dissatisfied with the referral service and DEIC staff (behaviour and availability) in Indore while in Ujjain 65.3% were dissatisfied.
- 71.1% beneficiaries remained dissatisfied with regard to expenses, in Indore, while 63.4% were dissatisfied in Ujjain.

National Programme for Control of Blindness and Visual Impairment (NPCBVI)

In 1976, GoI launched the National Programme for Control of Blindness with the goal of reducing the prevalence of blindness. From 2017 onwards, the programme was strengthened and expanded to cover all kinds of visual impairment. It includes development of comprehensive eye care services along with a focus on childhood blindness. The programme has three major activities (a) cataract surgeries; (b) corneal collection; and (c) distribution of spectacles to school children.

At the national level there seems to be an increasing focus on providing free spectacles to school children suffering from refractive errors, however the targets are far from being achieved (figure 4).

Recent data on the number of school children provided spectacles is not available at the state level. However, as per the framework for implementation of **National Health Mission (NHM) 2020-21, the target for training and free spectacles to school children for the whole state was only 8570 with a mere sum of 30 lakhs allocated for the same. In recent years, the targets have**

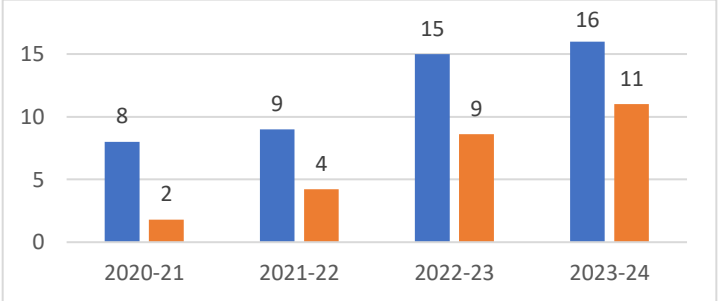

Figure 4: Free spectacles provided to school children suffering from refractive errors in India (numbers in lakhs)

increased, to 93,000 in 2024-25 and 97,000 in 2025-26. However, actual coverage needs to be monitored. Screening of children for refractive errors and providing of spectacles is critical not only for better functionality of the child but also to enable access to education. It is important for the state to focus actions and report data on the same.

National Programme for Prevention and Control of Deafness (NPPCD)

In 2007, GoI launched a pilot project under the National Programme for Prevention and Control of Deafness (NPPCD) in 25 districts of 11 States/UTs. By 2023-24, 595 districts in the country have been covered under the program (MoHFW, 2023-24). Under the programme screening, examination and rehabilitation is provided to identified hearing impaired persons. The core programme focuses on building institutional and human resource capacities and increasing public awareness on the issue. Hearing aids are provided as part of ADIP program, along with support for rehabilitation. **No data on coverage of children with disabilities in the state of Madhya Pradesh is available**.

National Mental Health Program (NMHP)

The GoI launched the National Mental Health Programme (NMHP) in 1982, to ensure the availability and accessibility of minimum mental healthcare for all in the foreseeable future, particularly to the most vulnerable and underprivileged sections of the population. It also aims to encourage the application of mental health knowledge in general healthcare and in social development and to promote community participation in the mental health service development. Again, **specific data on the treatment support provided to children with disabilities is not available** with the DHFW, GoMP.

> One key aspect of the NMHP Is to provide in-patient services to people with intellectual disabilities. As part of the National Health Policy (2017), this would mean providing support for creation of separate development appropriate facilities for children with disabilities at public hospitals and training professionals in the field to address the additional challenges faced by children with intellectual disabilities.

Subsequently the District Mental Health Program (DMHP) was launched under NMHP in the year 1996. The DMHP was based on 'Bellary Model' with the following components: (a) early detection and treatment; (b) imparting short term training to general physicians for diagnosis and treatment of common mental illnesses with limited number of drugs under guidance of specialist[12]; (c) public awareness generation through information, communication and technology (IEC) measures; and (d) monitoring the status of mental health. The DMHP is currently operational in 738 districts in India (MoHFW, 2023-24), including all districts in MP (RoP NHM (MP), 2024-26). Although there is a significant scope to target children, especially adolescents, as part of the programme, there is not data available on the same. Studies (Bhushan Girase, et al., 2022) suggest that the programme is oriented more to provide care for adults, and does not have a focused targeting of children with disabilities. Further, in the absence of systematic routine monitoring and information on the number of people receiving care for mental health problems, the extent of DMHP's functionality at ground level has not been comprehensively assessed (ibid).

Advocating the use of digital tools for improving the efficiency and outcome of the healthcare system, particularly in the domain of mental health care, the National Tele Mental Health Programme, Tele Mental Health Assistance and Networking Across States (Tele MANAS) was launched on 10th October, 2022 in the Union budget 2022-23 as a digital arm of DMHP. By end of March 2024, Tele MANAS was operational in all 36 States/ UT's through 51 functional Tele MANAS cells along with additional TMC being set up in collaboration with Aditya Birla Group Empower initiative in Nagpur (Maharashtra) (MoHFW, 2023-24). However, awareness regarding the facilities available seem to be very low among frontline functionaries as well as parents of children with disabilities. None of the people met as part of the study in Bhopal and Raisen, even mentioned the existence of the programme.

[12] The health workers are being trained in identifying mentally ill persons.

Assistance to disabled persons for purchasing / fitting of aids / appliances (ADIP)

Launched in 1981, Assistance to disabled persons for purchasing / fitting of aids / appliances (ADIP), is a central sector scheme requiring no state-wise allocation of funds. Under ADIP, funds are released to various implementing agencies to assist persons with disabilities including intellectually challenged, in all the states for procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances. It is expected that this will promote physical, social and psychological rehabilitation of people with disabilities by reducing the effects of disabilities and enhance their economic potential. The scheme also envisages conduct of corrective surgeries, whenever required, before providing an assistive device. The scheme has been revised recently wef September 2024, with the objective to make it more inclusive and more user friendly. The revised guidelines have simplified various provisions of the scheme incorporating latest guidelines issued by Department of School Education and Literacy, Ministry of Education, GoI. The quantum of financial assistance is limited to 15000 INR. However, the revised scheme also promotes contribution of funds through Corporate Social Responsibility (CSR), MP-MLA-LAD Fund, state government, panchayat, municipal corporations, mineral fund, etc.

There are certain conditions for availing benefits including: a) holding a UDID card along with Disability Certificate with at least 40% disability; b) having a Aadhar card; c) having a monthly income of individual from all sources not exceeding Rs.30,000/- per month and in case of dependents, the income of parents/guardians not exceeding Rs. 30,000/- per month; and d) not having received assistance during the last 3 years for the same purpose from any source.

The scheme has specific provisions for children with disabilities including a separate ADIP SSA[13] (Samagra Shiksha Abhiyan) component. The key provisions include:

- **In case of less than 40% disability, aids and assistive devices can be issued to children with special needs (CWSN) based on the joint certification** from the (i) Headmaster or Principal of the school (ii) Local SSA Authority and (iii) RCI registered rehab professional with active CRR No. from Artificial Limbs Manufacturing Corporation of India (ALIMCO).
- Temporary Disability Certificate issued by the competent medical authority for children up to the age of 6 years or Developmental Delay Certificate issued by competent medical authority for children up to the age of 6 years may be considered for distribution of teaching learning material (TLM) kits[14] under ADIP Scheme to persons with Intellectual and Developmental disabilities as approved by the Ministry. However, here there is no dilution of the condition of minimum 40% disability as stipulated in the ADIP scheme.
- Benefits of **ADIP SSA are also extended to children till the age of 18 years who are studying in special schools, home schooling or to walk-in at ALIMCO/National Institutes/Composite Regional Centres (CRCs)**. For this purpose, a committee needs to recommend the necessary aids and assistive device to that beneficiary in case of less than 40% disability or having no disability certificate.
- **For children below 18 years of age, the minimum time of assistance is one year** for customized items like fitments of orthosis / prosthesis, learning material etc. (except motorized tricycle/ motorized wheelchair and smart phone once in a five year).

> The committee shall comprise of 02 officials in the manner as under:
>
> (a) One RCI Registered Rehab Professional/P&O of ALIMCO/ NI/CRC and
>
> (b) One member from the Education Department of the concerned State.
>
> However, the status of the committee in the state of Madhya Pradesh is not very clear.

[13] Under ADIP SSA, Aids and assistive devices are distributed to children below 18 years of age and those attending Schools under the Samagra Shiksha Abhiyan Scheme of the Ministry of Human Resource Development (MHRD). As per the agreement with the Ministry of HRD, ALIMCO, the implementing agency, is reimbursed 40% of the expenditure by MHRD and remaining 60% of the expenditure by the department through grants under ADIP Scheme.

[14] These kits contain various materials and tools that can be used to support learning and development in areas like cognitive skills, fine motor skills, and sensory integration.

- Under the ADIP-SSA scheme, motorized tricycle can be provided to school-going students having UDID Card/ Enrolment Number of UDID Card along with at least 40% disabilities certificate issued by competent authority to the students studying in Class IX to XII not below the age of 16 years.
- Income certificate of beneficiaries staying in orphanages and half-way homes/special school/special home etc. to be accepted on certification of District Collector or Head of the organization concerned. Such beneficiaries, however, can be provided aids and appliances under this scheme by ALIMCO/NIs/CRCs only.

It is critical to review the coverage of ADIP SSA among children with disabilities in the state of Madhya Pradesh. Unfortunately, though, there is no specific recordkeeping of the data at the state level (possibly due to it being a central sector scheme with no state allocations).

Furthermore, even at the national level, reporting under ADIP is more concentrated at an overall level, with no separate state-wise data on ADIP SSA reported even in the annual report of the DoEPwD (GoI). Data compiled from various sources as part of the research has been presented in table 3.

Table 3: Number of beneficiaries covered under ADIP SSA in Madhya Pradesh

Source of data	2020-21	2021-22	2022-23	2023-24	2024-25	Total
Lok Sabha Unstarred Question No. 2048 (2023)	6918	15352	10690	-	-	32,960
Lok Sabha Unstarred Question No.2441 (2024)	-	-	-	-	-	38,225
SJED (GoMP) (No of Beneficiaries)	0	4290	3359	2446	0	10095
SJED (GoMP) (No of Appliances)	0	7584	5721	4380	0	17685

It is clear from the above that the state government has very little information on the coverage under ADIP SSA. Considering this, one of the major actions required is the **need for having a common database of all beneficiaries** covered in the state, which is accessible to both central and state officials. Without adequate data, it is not possible to monitor the coverage and implementation status of the scheme. The Samagra platform of the GoMP can be used to collate data on provision of assistive technology under ADIP to children with disabilities in the state.

As such given the current status, **the coverage seems to be highly inadequate**. As per census 2011 itself, the number of children with disabilities in the state (0 to 19 years) is 4.63 lakh. If one were to assume that only 30% of the children (1.39 lakh)[15] require support of assistive technologies, the coverage even for the total of last five years is only 27.5%. Considering that children are entitled to annual customized upgrades, the coverage of even the maximum of 15,352 in any year would hardly be 11%. Even if one were to only consider the coverage of CWSNs under ADIP SSA given the focus on linkages with schools, the target would be 1,38,593 (UDISE+, 2021-22), the coverage figures are low. The target assuming 30% requirement would be around 41,558. Of this only 91% seem to have been covered once in the last five years, with an annual coverage of only 36.94%. It is highly critical, that the SJED sets a coverage target, undertakes specific actions especially for awareness generation for increasing the same and monitors the results.

Another key gap area, revealed during the key informant interviews was that while ALIMCO organizes camps in schools and community for needs assessment of children with disability in terms of assistive devices and also distributes devices as per the need and age of the child, including progressive devices, there is a time lapse between assessment by ALIMCO on assistive device needs of child and provision of service, which often results in the assistive device, when actually provided ,not remaining relevant

[15] 30% target would be logical considering that as per census 2011, around 2.73 lakh children only had seeing, hearing, speech and movement difficulties. If we assume half of them could be supported, then the overall target would be around 29.46 or 30% of the overall population of children with disabilities in the state.

for the growing child. This could also be the reason for the lower coverage among children under ADIP SSA. The SJED, needs to have better coordination with ALIMCO to enable timely provision of the devices, through a tracking mechanism.

It is important to mention here that although ADIP SSA has a specific provision for children in care institutions (CCIs), there currently seems to be no coverage of children with disabilities in CCI as part of the scheme. During key informant interviews, WCD Department, GoMP, revealed that data on such children is currently not available. The WCD agreed to collate the data in near future and working in collaboration with SJED and ALIMCO to organize specific camps for children with disabilities in CCIs.

One clear missing group in the state of Madhya Pradesh is children with disabilities in child care institutions (CCIs). Currently, there is no data available on the number of such children with the Department of Women and Child Development (WCD). Further there is also no convergence with SJED or ALIMCO to undertake assessment camps and provide assistive devices to children with disabilities in CCIs. SJED and WCD should work together to organize a dedicated camp for children with disabilities through ALIMCO.

The scheme also specifically provides for **cochlear implant and post operative therapy and rehabilitation for children with hearing impairment with a ceiling of Rs. 7.00 lakh per unit** (to be borne by the government) in case of children with pre-lingual hearing loss between 1 to 5 years of age and Rs.6.00 lakh in case of children with acquired hearing loss between 5 to 18 years. The financial support covers the cost of implant, surgery, therapy, mapping, travel and pre-implant assessment in both cases.

Here again, there is a dearth of data on coverage at the state-level. Available data in the public domain (LSUQ 3003, 2023), however, shows that the state has very less coverage especially compared to other large state like Karnataka, Gujarat, Haryana, etc (figure 5).

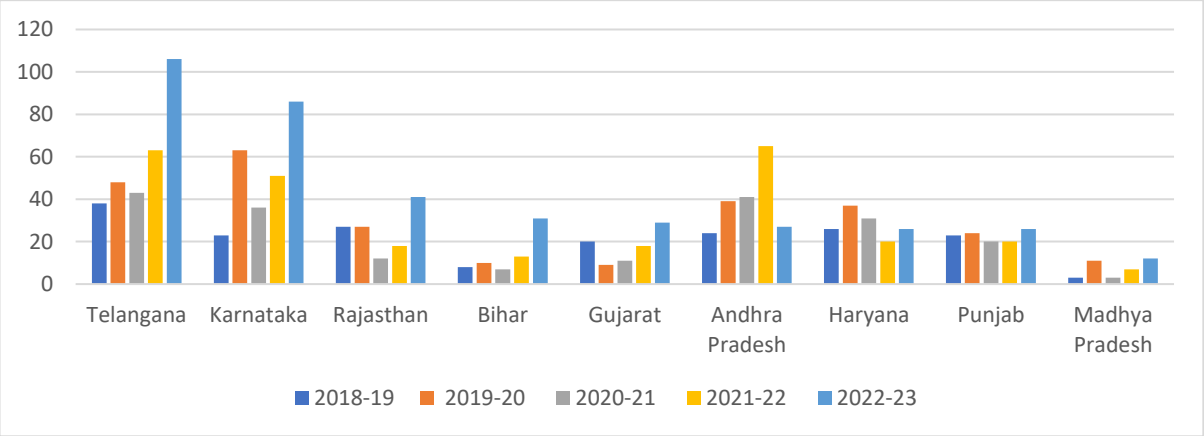

Figure 5: Cochlear implant surgeries conducted in various states in last five years

This is not surprising given that even though there are 19 empanelled hospitals in the state, in FY 2022-23 by the end of October 2022 only one (1) surgery was performed in the state (Ali Yavar Jung National Institute of Speech and Hearing Disabilities (Divyangjan), 2022). This not only points towards lack of awareness among beneficiaries to seek support, but also inadequacy of efforts to reach out to potential beneficiaries in the absence of a sound monitoring mechanism at the state level.

An important aspect of the monitoring would be getting separate details of funds utilized for ADIP SSA and under ADIP (including CSR) specifically for children with disabilities. Currently information available in public domain is only for overall ADIP (figure 6).

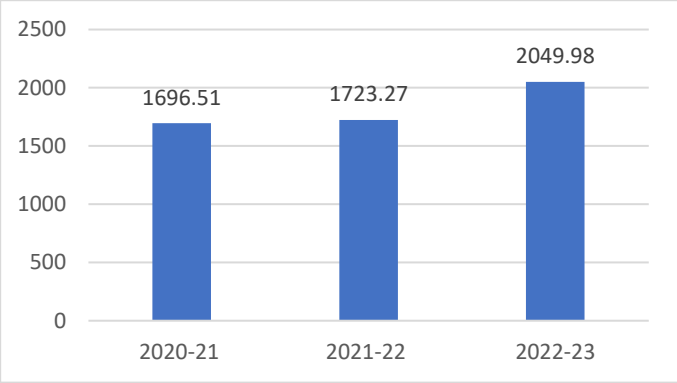

Figure 7: Details of funds utilized for ADIP in Madhya Pradesh (amount in Lakh rupees)

Source: LSUQ 3003 (2023)

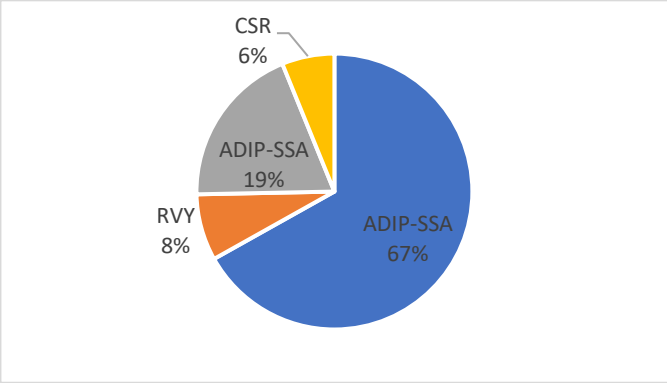

Figure 6: Proportion of value of assistive devices provided under different type of ADIP in Madhya Pradesh (2020-25)

Source: Data received as part of the study from SJED, GoMP

While the state has some data in terms of value of services provided under ADIP (table 4), it seems very incomplete given the much lower numbers being reported compared to national figures. Furthermore, from the state figures it seems that less than 20% of the allocations is for ADIP SSA even though children with disabilities are almost 30% of the population of persons with disabilities in the state (figure 7). It is important for the state to focus more on allocations under ADIP for children with disabilities.

Table 4: Value of assistive devices provided under ADIP in the state over the years (In Lakh Rupees)

Details	2020-21	2021-22	2022-23	2023-24	2024-25 (Until Jan 2025)	Total
ADIP	568.23	280.28	1,325.10	508.11	269.06	2,950.78
Rashtriya Vayoshri Yojana (RVY)	47.79	201.06	75.65	0.88	18.78	344.15
ADIP-SSA	0.00	387.00	270.45	188.01	0.00	845.47
CSR	37.84	40.27	46.36	67.95	79.42	271.83
Total	**653.86**	**908.61**	**1,717.56**	**764.96**	**367.26**	**4,412.24**

Source: Data received as part of the study from SJED, GoMP

Deendayal Disabled Rehabilitation Scheme (DDRS)

In 2003, the amalgamated central sector "Scheme to Promote Voluntary Action for Persons with Disabilities" was renamed as Deendayal Disabled Rehabilitation Scheme (DDRS). The scheme has since been revised multiple times with the latest guidelines effective from 1st of October, 2024. The approach of this scheme is to provide financial assistance to voluntary organizations to make available the whole range of services necessary for rehabilitation of people with disabilities, including early intervention, development of daily living skills, education and training. Provisions of Home-Based Rehabilitation (HBR) and Community Based Rehabilitation (CBR) have been kept in all projects except two newly started projects. Different types of model projects are supported under DDRS, with a few targeted specifically for children with disabilities (table 5). As can be seen the focus of 5 of the 6 model projects seems to be more in terms of education rather than therapy and counselling services.

Table 5: Model projects under DDRS and key entitlements

Sr. No.	Model project	Target Group	Key Entitlements
1.	Cross Disability Pre-Schools and Early Intervention with provision for HBR and CBR projects.	Infants and children up to 6 years of age	▪ Prepare the children for their schooling in special schools and/or integration at the appropriate stage in regular schools for inclusive education. ▪ Classes for at least 6 hours with hot cooked meals
2.	Special School for the children with Hearing Disability with option for HBR and CBR projects.	5-18 years of age	▪ Provide for residential as well as non-residential care to acquire skills for basic activities of daily living ▪ Development of language and communication skills and academics ▪ Classes for at least 6 hours with hot cooked meals ▪ Teacher-pupil ratio is kept at 1:8 ▪ Transport allowance, Stipend and Hostel Maintenance
3.	Special School for the children with Visual Disability (including Deaf blindness) with option for HBR and CBR projects and Low Vision Centre Project.	5-18 years of age	▪ Provide for residential as well as non-residential care to acquire skills for basic activities of daily living ▪ Development of communication skills and development of other sensory abilities ▪ Classes for at least 6 hours with hot cooked meals ▪ Teacher-pupil ratio ranges from 1:8 to 1:15 ▪ Transport allowance, Stipend and Hostel Maintenance
4.	Special School for the children with other disabilities (ID/CP/ASD/MD/ Muscular Dystrophy, Deaf blindness etc) with option for HBR and CBR projects.	5-23 years of age	▪ Provide for residential as well as non-residential care to acquire skills for basic activities of daily living ▪ Expected to bring about behavioural changes and enhancement of their cognitive abilities ▪ Teacher-pupil ratio is kept at 1:4 ▪ Attendant-pupil ratio is kept at 1:8 ▪ Transport allowance, Stipend and Hostel Maintenance
5.	Preparatory / Remediation Centre for Children with Specific Learning Disabilities to continue Inclusive Education Project.	3 to 18 years of age	▪ Learning the lagging concepts by using alternative education methods like remedial teaching, reconstructive teaching etc and enabled to continue the inclusive education.
6.	Cross-Disability Therapy and Counselling Centre	No age bar	▪ Assist children and adults with any type of disability (as specified in RPD Act, including Acid-Attack victims) for their therapeutic or counselling needs

In terms of actual progress, as per the DoEPwD Annual Report of 2023-24, there were 12 DDRS projects being supported in Madhya Pradesh. All the projects seem to be targeted for children with disabilities, as is reflected from the data on beneficiaries reported by DoEPwD to the Lok Sabha (table 6).

Table 6: Beneficiaries under DDRS in Madhya Pradesh over the years

Details	2020-21	2021-22	2022-23	2023-24
Total number of beneficiaries[1]	822	682	803	764
Number of beneficiaries children[2]	822	682	803	NA
Percentage of child beneficiaries	100%	100%	100%	NA

Source: 1. DoEPwD Annual Report (2023-24); 2. LSUQ No 2048 (2023)

The number of beneficiaries covered under DDRS depends highly on the Grant in Aid (GIA) released to the state. It is good to note that this has been steadily increasing over the years for the state of Madhya Pradesh (figure 8). Data on actual utilization for the state is not available, however, at the national level the standing committee on social justice and empowerment for the 18th Lok Sabha in its report of 2024-25 has pointed out that "While *the DDRS has made progress in reaching its targets, there are significant challenges in fund utilization and physical achievements. The Committee note that there were variations in actual expenditure, as only 56 per cent utilized in 2022-23 and 15 per cent utilized as of November 2024 for 2024-25, indicating inefficiencies in fund disbursement and implementation. The Committee would like to recommend that the Department enhance fund utilization efficiency by streamlining the disbursement process and implementing real-time tracking mechanisms*." The committee has also recommended strengthening the monitoring and reporting system. The state governments need to undertake a more active role towards this. With no state-level studies to review the status of the DDRS in the state, it is important to understand the status of implementation of DDRS scheme in the Madhya Pradesh better. The SJED should undertake a specific research project towards understanding the status of fund utilization and quality of implementation of DDRS in Madhya Pradesh.

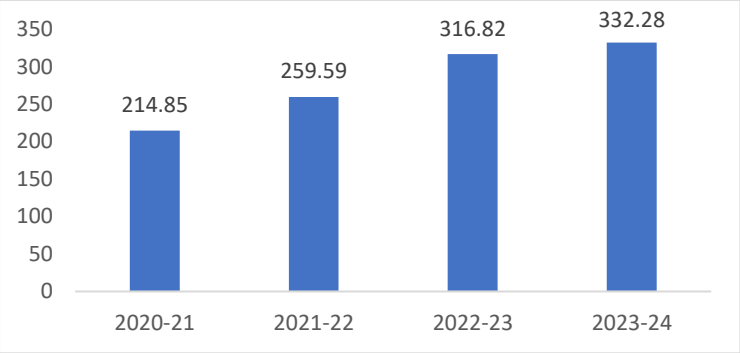

Figure 8: Funds released in last few years under DDRS scheme to Madhya Pradesh (amount in in lakh rupees)

Source: LSUQ NO 3008

District Disability Rehabilitation Centres (DDRC)

The District Disability Rehabilitation Centre (DDRCs), is a sub component under the DDRS for providing comprehensive rehabilitation services to people with disabilities at district level which includes early detection and intervention; counselling and medical rehabilitation; and assistance in procuring appropriate aids and appliances for reducing the effect of disabilities. GIA is provided to state governments and various other bodies, set up by the central and state governments, to support various activities. DDRC is run under the supervision of a District management team (DMT) headed by the District Collector. DMT includes district officials from Social Welfare, Health, Panchayati Raj, Women and Child Welfare Departments, nodal officer from implementing agency and representative from reputed NGOs. The working of DDRCs is reviewed by the DMT from time to time and grants are released only on the recommendation of the DMT and the state governments.

Interestingly, while 325 districts were initially identified for establishing DDRCs, it was set up in only 269 districts. Presently all districts of the country are authorized to establish DDRC. However, by end

March 2024, only 87 DDRCs were functional (including the newly inaugurated ones) (Department Standing Committee, 2024-25).

Madhya Pradesh has set up of DDRCs in all districts. However, as per the DoEPwD Annual report (2023-24), the central provided GIA to only 27 DDRCs. Under the DDRC scheme, GIA is released only against proposals which are complete in all respects as per the scheme guidelines. In 2021-22, there were 51 proposals from the state covering all districts (RSUQ 3803, 2023). However, in 2022-23, the number of proposals dropped to 31. This seems to have further declined in 2023-24.

While updated data was not available at the state level, review of some older data publicly available, shows that the actual amount of GIA released is very minuscule (figure 9). It is critical for the state to ensure that all DDRC's receive the GIA from the central government, in a timely manner, so as to maintain the required levels of infrastructure and service quality.

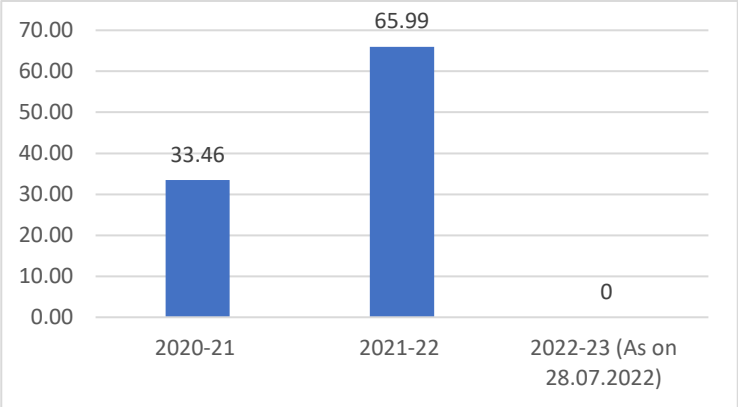

Figure 9: Grants-in-Aid released to DDRCs in Madhya Pradesh during the previous years (amount in lakh rupees)

Source: RSUQ No. 2056 (2022)

Maintaining infrastructure and service quality across all DDRCs is in fact crucial, given that they are often the only rehabilitation centre available at the district level. The national government facilitates independent evaluations for the same. The last third-party evaluation was conducted by National Institute of Labour Economics Research and Development (NILRED) in the year 2020-21 has found the working of DDRCs as satisfactory. However, reports on the ground suggest otherwise. Field visit to Raisen district and key informant interviews highlighted the following points:

- The DDRC has a separate building and lot of space both constructed and open land. It also has all basic infrastructure including staff rooms, therapy rooms and accessible toilets. Interestingly though, the number of male toilets was double that of female toilets. Accessibility features in the DDRC, however, need to be improved.
- The DDRC building needs to be made more attractive with paintings and landscaping. There is lot of space to even make a small accessible playground for children.
- Some of the rooms are currently simply being used as storage for ALIMCO provided devices. These can be converted into more usable rooms like library, audio-visual or playroom.
- The DDRC has a staff of 8 people including a physiotherapist, speech therapist, and mobility instructor; and administrative staff. There are a total of 15 approved positions. A new coordinator is expected to take charge soon.
- The mobility instructor and speech therapist also had access to tools for teaching and learning. However, the physiotherapist had no tools/equipments to use- not even a bed, cycle or ball. It might be difficult to provide regular physiotherapy under such circumstances.
- Training of staff is an issue of concern. While the staff is qualified and takes up some additional courses as part of the registration renewal process, they have very limited access to formal training from the department or government. The staff especially wanted training on new technologies like using telescope, daisy player, braille watch, etc. Annual trainings for staff should be considered.
- Awareness about the DDRC is very limited and hardly much communication activities seem to being undertaken. Most of the outreach was through attending medical board assessment days

every Wednesday at the district hospital or camps for disability certification and provision of assistive devices.

- No early detection activities are currently being undertaken by the DDRC. Although the DDRC staff mentioned that they had an active linkage with local anganwadi centres at ward 1, 3, 7 and 12. However, even the WCD supervisor (just working in the next-door building) was not aware of the DDRC activities.
- Regular therapy for children with disabilities is also a major need. However, while already existing services are limited, there are addition issues related to accessibility and availability of equipments at district hospitals and DDRCs.
- Regarding usage of the services by children with disabilities, it was discussed that most children come to the centre only in the afternoon and that too only from Raisen town.
- Many parents are not aware of the services available at the DDRC. Even when aware, they are not able to bring the child regularly for the required therapy due to time and transportation constraints.
- People from villages find it very hard to bring their children to the centre for therapy on a daily basis, since its very far and also as most parents are poor and do not want to miss their daily wage labour. There is a complete lack of accessible transport facilities available for children with disabilities to visit the DDRC.
- Besides, awareness on the importance of therapy itself is very low. Additionally, awareness on how to get it, understanding on how long will it be required and how it will make life easy for children later is also not there. Medical professionals also don't seem to be guiding parents towards the same.
- It needs to be noted here that the minimum time for therapy is 30 days for walking (mobility), two years for braille and one to five years for those with intellectual disabilities. The team mentioned that they also undertake parent sessions so that follow up actions can be undertaken at home.
- There are also a few instances when the parents are worried that if the child recovers and moves below benchmark disability (40%) level then they might lose the disability pension.
- In one case (which does not seem as exception) there seemed to be satisfaction with just receipt of disability pension, with limited concern about the child's future once the second child was born. This point was also reiterated by other informants (at DDRC and district hospital) as being the key point for parents, especially those from poorer backgrounds, for not seeking services. There also seems to be a fear that reduction in disability percentage can cut on pension, while not adding any benefits.
- The ratio of students seems interesting with 60% having speech impairment, 30% having locomotive impairment, and 10% visual impairment. Although actual data was not available handily, it was reported that most of the users are boys.
- The team also met a client who had come to drop his nephew for therapy and saw the staff interacting with him. The staff seems to know their job, and with all basic infrastructure, it can be converted into a model DDRC.

The findings from the field visits reveal the vast potential that DDRCs have in addressing the needs of children with disabilities. The GoI is also simultaneously making efforts towards building their quality through promotion of model DDRCs. In September 2022, nine (09) model DDRC were promoted as part of phase I. However, it did not include any from Madhya Pradesh. The CSR website of GoMP, shows a proposal for DDRC Umaria to be set up as model DDRC with a proposed budget of 18.30 lakhs. However, open since 2020, no progress has been made yet. It is important for the SJED to liaise with CSR initiatives more proactively for setting up of model DDRCs in the state.

Composite Regional Centre (CRC), Bhopal

The GoI has also set up nine National Institutes (NIs) and 21 Composite Regional Centres (CRCs) for survey and identification of persons with disabilities and provision of rehabilitation services; aids and assistive devices; therapeutic services; counselling, awareness generation; professional capacity building; research; etc. One CRC has also been established in Bhopal, providing direct services to many people with disabilities. Although separate details related to children is not available, a review of overall beneficiaries covered during last three years shows an increasing trend (figure 10). It is also interesting to note that among all the 21 CRCs in the country, in 2020-21, CRC (Bhopal) stood fourth in terms of number of beneficiaries covered (RSUQ No. 2056, 2022).

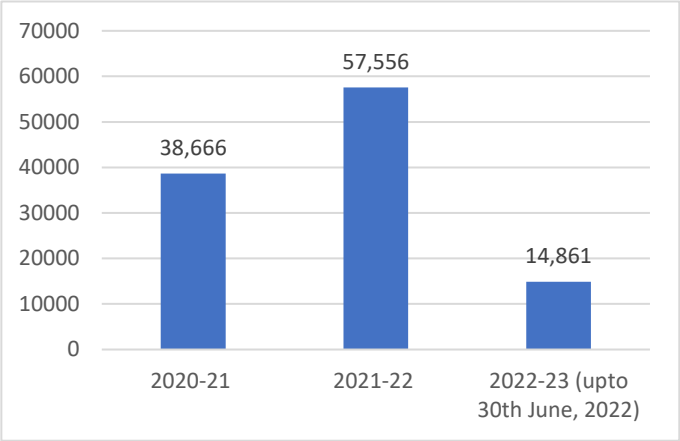

Figure 10: Beneficiaries covered by Composite Regional Centre, Bhopal in previous years

Key issues and Recommendations

Reliable estimates of children with disabilities and research studies on concerns at state level are not available

- Primary survey using the "Child Functioning Module" developed by UNICEF and Washington group needs to be conducted to get better estimates to children with disabilities.
- Screening all the children needs to be undertaken at least once in a year for the purpose of identifying "at-risk" cases.
- Research study using primary data collection needs to be undertaken to understand the status of health and nutrition of children with disabilities in the state.
- Publish a primer on the status of children with disabilities in the state based on the national family health survey (NFHS).
- Undertake a study on the profile of drop-outs from full immunization programme, and on identification of barriers and challenges for children with disabilities to be fully immunized.
- Small research studies on status of DEICs, DDRS and DDRCs in select districts need to be supported at regular levels.

Early detection and treatment are still a challenge

- The child screening rate under RBSK needs to be improved with setting of higher targets and more effective integration with anganwadi centres, DDRCs and CCIs for reaching out to out of school children with disabilities.
- The RBSK can in fact consider having a separate drive/camps every six months for screening of children with disabilities.
    - The drive should be separated from any link with UDID registration to ensure the focus is on identification of all children with disabilities and not only on children with benchmark disabilities.
    - Increased involvement of gram panchayats and urban local bodies should be there in conducting of these drives at local level. There should be a specific focus on sensitization of elected representatives from gram panchayats and urban local bodies for enabling this.
- Provision of incentive to ASHA worker for ensuring referral follow ups, at secondary and tertiary care, for children especially girls with disabilities screened under RBSK can be explored.
- Increasing focus on providing free spectacles to school children suffering from refractive errors.

Increase coverage of children with disabilities under existing health and nutrition programmes

- Undertake special drives for providing Swavlamban Cards for the empowerment of children with disabilities and their families under Poshan Abhiyan.
- Anganwadi services especially THR provision can be extended to children with disabilities between 6 to 18 years, who are not attending any educational institution.
- A special day in the Anganwadi centres should be organized every month for children with disabilities, wherein they can be provided with growth monitoring services, immunization update, vitamin A supplementation, iron supplementation and deworming medicine for worms' infestation, as well as information on therapeutic services and other government schemes. The programme should be led by WCD in convergence with SJED and Health department.
- Focus on targeted awareness and drives for enrolment of children with disabilities under the Ayushman Bharat scheme.
    - This could be further strengthened by addition of a top-up incentive to beneficiary facilitation agencies (BFA) to undertake screening and facilitate enrolment of such children and attend to the needs of beneficiaries, especially timely submission of treatment claims.
    - The state could also consider addition of a top-up under Ayushman Bharat for coverage of all children with disabilities under the scheme irrespective of their financial status.
- Develop a standard and set up separate, developmentally appropriate facilities for inpatient treatment of minors as required under the new Mental Health Act. These can be developed at select district hospitals/medical colleges in Bhopal and one in each region of the state.

Access to therapeutic services and assistive devices seems inadequate

- Set up separate targets and facilitate increased coverage of ADIP SSA in the state.
- Conduct awareness campaigns and drive for increased coverage of beneficiaries under cochlear implant and post operative therapy and rehabilitation for children with hearing impairment.
- Funding for DDRCs need to be increased.
    - Develop proposals for DDRCs in line with scheme guidelines and ensure that central funds are received by all DDRCs in a timely manner. SJED should track the GIA flow to DDRCs on a semi-annual basis.
- Improve the quality of infrastructure and services provided at the DDRCs and promote child friendly DDRCs.
    - Undertake a design workshop/assessment exercise on "making DDRCs child friendly" and develop a model protocol/ guideline for child friendly DDRCs development.

Box 2: Upgrade one DDRC into model DDRC

- The DDRC can be linked with a select CSR foundation for infrastructure upgradation including provision of a vehicle.
- External wall painting of the DDRC needs to be done in bright and contrast colours keeping visibility in mind.
- A proper entrance board for the DDRC, with banners, boards on the boundary wall highlighting the services provided need to be placed.
- Landscaping in the campus with fruit and vegetable gardening to be undertaken. This can then be converted into a gardening activity for children (even adults) coming to the centre.
- The reception needs to be upgraded significantly- staffed and made accessible and visually appealing. The reception should act like a district level help-desk for all programmes related to persons with disabilities. A 9 to 5 information help-line can also be managed at the reception to provide information on government schemes and services for people with disabilities.
- Set up a computer centre to enable people with disabilities especially students to avail free usage of computer and internet for filling of college forms, government service application, etc.

- Develop a small playground with accessible swings and play equipments for children with disabilities.
- Inside the DDRC, wall paintings can be undertaken, depicting positive initiatives for children/persons with disabilities (for example working in retail shop or as a computer programmer, para-Olympians).
- Create a play room with trampoline set, games and audio-visual facilities for children.
- Create a physiotherapy room with all necessary equipments (see list provided by the centre).
- Establish a pick-up and drop service for children with disabilities within Raisen block to begin with to come to the centre (if necessary, accompanied by caretaker).
- Accessibility audit of the DDRC needs to be undertaken and all required features implemented.
- Develop an exhibition room for all ALIMCO provided assistive devices (beyond wheel chairs, cane and crutches) inside one room with posters on how to use the same.
- Develop an art room with training and creation facilities for painting, pottery, etc in the DDRC.
- Once the DDRC is developed conduct exposure visits for Sarpanches, Anganwadi workers and supervisors, teachers and Self-Help Group (SHG) leaders, Primary Health Centre Doctors, to the DDRC, for awareness raising.
- The model can be documented and costed to convert into an "adopt a DDRC" programme for CSRs.

- Awareness camps on need for therapies and services provided by the DDRCs should be conducted in all districts.
- The feasibility of designing a pilot programme for provision of subsidized transport facilities for children with disabilities to come to DDRC for therapy for around 90 to 120 days should be explored.
- Provide rehabilitative services at multiple levels (daycare and residential care, routine psychosocial activities, outreach activities, livelihood activities, etc.); and set up integrated CBR programs by involving various stakeholders. Increase the number of proposals sent from the state under the DDRS scheme.
- Consider increasing the number of Rehabilitation Council of India (RCI) certified professionals being employed in the DDRCs through targeted recruitment drives.
- Internship programmes linked with RCI could also be explored to encourage students studying in related fields to have hands-on experience of working for children with disabilities.

Children with disabilities especially those in Child Care Institutions (CCIs) falling between the cracks

- Specific camps need to be undertaken through RBSK to identify children with disabilities.
    - Provisions need to be made for referral and follow up to ensure children with disabilities in CCIs are provided the necessary treatment.
    - Children with benchmark disabilities, eligible for UDID should be supported for registration.
    - Other children with disabilities (less than 40%) should also be provided with disability certification for benefits under other programmes.
- A targeted programme for children with disabilities in CCIs needs to be undertaken for covering the following services:
    - Mandated provision of fortified food material to CCIs on lines of Poshan Aahar and PM Poshan schemes
    - Camps for vitamin A supplementation, iron supplementation and deworming medicine for worms' infestation, under NHM for children with disabilities in CCIs need to be organized.
    - Quarterly camps should be facilitated with support of ALIMCO and CRC (Bhopal) for assessment and provision of assistive devices to children with disabilities in CCIs.
    - Counselling programmes should be conducted at regular intervals to support children with intellectual disabilities living in CCIs.

Anganwadi centres, Primary Health Centres (AAMs), District Hospitals, even DDRCs are not suitably accessible.

- SJED should consider commissioning an accessibility audit for all District Hospitals and DDRCs in first phase and Anganwadi centres and Primary Health Centres (AAMs) in second phase.
- Based on the audit findings the respective departments should develop proposals and submit under SIDPA for ensuring accessibility of all buildings providing services to children with disabilities.

Training modules need to be developed and regular trainings of frontline workers and medical professionals needs to be undertaken

- Partner with select national institutes for conducting an advanced (5 days) training for different specialist at the DDRCs.
    - National Institute for the Empowerment of Persons with Visual Disabilities (NIEPVD), Dehradun
    - Ali Yavar Jung National Institute of Speech and Hearing Disabilities (AYJNISHD), Mumbai
    - Pt. Deendayal Upadhyaya National Institute for Persons with Physical Disabilities (PDUNIPPD), Delhi or National Institute for Locomotor Disabilities (NILD), Kolkata
    - National Institute of Mental Health and Rehabilitation (NIMHR), Sehore
- Partner for development of refresher (2 days) training modules for different types of disabilities.
    - Organize dedicated trainings for all therapist at the DDRCs every six months (25 people per training) at Composite Regional Centre for Skill Development, Rehabilitation & Empowerment of Persons with Disabilities (CRCs)
    - Refresher trainings should be mandatory for all staff at least once every two years.
- Training of all Anganwadi workers on MWCD's protocol on "Anganwadi Protocol for Divyang Children" needs to be undertaken.
- Specific training of Anganwadi and ASHA workers for supporting adolescent girls with disabilities on menstrual hygiene and use of sanitary products.
- Organize workshops and seminars on issues of children with disabilities for medical professionals at state and district level.
- Conduct training programmes for staff of public works department and related stakeholders (developer of detailed project reports, contractors, etc.) on accessible and inclusive infrastructure development.

Tracking of children with disabilities under general schemes not happening

- Targets should be set for children with disabilities to be covered under all government schemes for children as well as those for people with disabilities.
- Tracking of data on children covered under ADIP SSA, DDRS and DDRCs at the state level should be initiated on a priority basis.
- Tracking of children with disabilities using POSHAN tracker and health cards for nutrition coverage and immunization services specifically needs to be undertaken.
- Tracking of services provided to children with disabilities under various national programmes especially related to blindness control and visual impairment, hearing impairments and mental health, needs to be undertaken.
- Tracking of coverage of children with disabilities under Ayushman Bharat programme, along with status of insurance claims needs to be undertaken.
- Strengthen implementation of PM-ABHIM to ensure sex, age and disability disaggregation (SADD) in health data.
- The state of Madhya Pradesh, which already has an integrated platform "Samagra" for targeted social protection services. Pilot a model for integration with health, nutrition and other services and separate tracking of data on children with disabilities.

- Tracking of girls with disabilities covered under Ladli Laksmi and Project Udita needs to be undertaken
- Tracking of beneficiaries having children with disabilities under Ladli Behna scheme also needs to be undertaken.

Ensure all required institutional mechanisms are in place

- An inter departmental committee for providing inputs to improve status of children with disabilities in the state can be formed with SJED, Health, WCD and Education departments on board.
- The SJED needs to set up a separate division for implementation and monitoring of coverage of children with disabilities under its various schemes. The division should also facilitate and review the status of implementation of central sector schemes such as DDRS, DDRC, etc.
- Mental health review boards (MHRB) to be operationalized across the state.
- Create a state-level portal integrated with Samagra platform for all data related to coverage of children with disabilities under various government schemes. The Samagra platform can specially be geared to monitor integrated coverage of services for children with disabilities.

Box 3: Investing for Children with Disabilities

A key aspect of all government actions for children with disabilities is the high dependency on central sector schemes. This means that the state is not actually investing in children with disabilities, resulting often in insufficient monitoring and review of implementation. It is important for the GoMP to develop its own schemes or top up funding for the well-being of children with disabilities. Interventions (also mentioned above requiring additional investments will include:

- New scheme for screening all the children needs to be undertaken at least once in a year for the purpose of identifying "at-risk" cases.
- Top-up scheme for THR provision to be extended to children with disabilities between 6 to 18 years, who are not attending any educational institution.
- Top-up under Ayushman Bharat for coverage of all children with disabilities under the scheme irrespective of their financial status.
- Pilot programme for provision of subsidized transport facilities for children with disabilities to come to DDRC for therapy for around 90 to 120 days.

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