Policy Brief 2024/25: Children with Disabilities in Madhya Pradesh (MP)
Achieving Health, Nutrition and Education Outcomes

Submitted to UNICEF Bhopal (MP)

Key messages and recommendations

1. **Reliable estimates of children with disabilities at state level are not available.**
Recommendation: Conduct a primary survey to get better estimates to children with disabilities and facilitate screening all the children at least once in a year to identify "at-risk" cases.

2. **Status of health, nutrition and education for children with disabilities is not clear. Very few data sets and research studies existing.**
Recommendation: Create a state-level portal integrated with Samagra platform for all data related to coverage of children with disabilities under various government schemes. Tracking of children with disabilities using POSHAN tracker and health cards needs to be undertaken. Publish annual reports/primers on status of children with disabilities. The state should also commission specific research studies to map coverage of services provided and barriers to access.

3. **Children with disabilities face poorer health, nutrition and education outcomes; while there are additional barriers in accessing services.**
Recommendation: Targets need to be set for coverage of children with disabilities under all health, nutrition and education programmes for children as well as those for people with disabilities and achievements should be monitored on a regular basis. Undertake specific drives and campaigns to create awareness and increase coverage of children with disabilities under government services.

4. **Anganwadi centres, Primary Health Centres (AAMs), District Hospitals, Schools, even DDRCs are not suitably accessible.**
Recommendation: Commission an accessibility audit for all District Hospitals, Primary Schools and DDRCs in first phase and Anganwadi centres, Primary Health Centres (AAMs) and Secondary Schools in second phase. Based on the audit findings, submit proposals for retrofitting of institutions to enable accessibility.

5. **Availability and quality of frontline staff and professionals is key.**
Recommendation: Conduct regular trainings of all frontline workers- DDRC staff, anganwadi and Asha workers, medical professionals and teachers on concerns of children with disabilities. Organize workshops and seminars to sensitize wider ambit of professional services providers.

6. **Institutional mechanisms to target and address the specific needs of children with disabilities are absent.**
Recommendation: Set up an inter departmental committee for providing inputs to improve status of children with disabilities with SJED, WCD, Health, and Education departments on board. Set up a separate division under SJED for children with disabilities.

PART 1 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 health, nutrition and education status and concerns of 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;
- ⇨ 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.

PART 2 SITUATION OF CHILDREN WITH DISABILITIES

As per census 2011, there were 4.63 lakh children with disabilities[1] in Madhya Pradesh. A high 71% of the children with disabilities reside in rural areas, while only 29% reside in urban areas. Most of the children with disabilities (59%) reported are 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%). Interestingly, the proportion of girls with disabilities is only 44%, which is lower than the overall girl child proportion of 48% in the state.

Unavailability of reliable and updated estimates of children with disabilities is a crucial challenge. At only 1.46% of child population, the census-based estimations are probably 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]. It is important to undertake a primary assessment to estimate the actual number of children with disabilities in the state.

Global studies (UNICEF, 2022) show that children with disabilities face poorer health outcomes than

[1] Census 2011, provides data for children in the age group 0 to 19 years. This would be currently around 4.55 lakhs based on projected population for 2021 and proportion of children with disabilities among total child population in census 2011.

[2] As per World Health Organization (WHO, 2011), globally the proportion of world population with a disability is 15%.

those without disabilities, but access to health care is limited. They have five times greater odds of reporting having been seriously ill in the last year than those without disabilities (H. Kuper, et al., 2014). Children with disabilities are also more likely to report episodes of diarrhoea, acute respiratory symptoms and fever than children without disabilities (UNICEF, 2021). Access to health care, however, is limited. UNICEF (2022) also quotes data showing that children with disabilities often do not receive basic treatment for common childhood illnesses and there is often a significant delay in seeking medical care especially for children with intellectual and developmental disorders (UNICEF, 2021). Children with disabilities are most likely to miss out on vaccinations than their peers without disabilities (UNICEF and LCDIDC, nd).

Malnutrition levels are also higher than other children. Children with disabilities are 42% more likely to be underweight, 25% more likely to be wasted and 34% more likely to be stunted (UNICEF, 2021). They also often miss out on the benefits from school-based nutrition programmes as they are less likely to attend school than their peers without disabilities (Groce, Nora, Eleanor Challenger, and Marko Kerac, 2013).

Additionally, the requirements of therapeutic support and assistive technologies is also often unmet. 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. For the vast majority of children with disabilities, inadequate access to assistive technology, further 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).

Despite widespread agreement on the importance of education, children with disabilities have lower school enrolment. Indications from available reports (UNICEF, 2022), shows that children with disabilities not only miss out on early learning, but are also more likely to never attend school or drop out in the very early stages of primary education. In case of the state, enrolment in schools itself has been highlighted as a major challenge. In 2023-24 (UDISE+), reported that only around 1,46,932 children with disabilities (reported as children with special needs) were enrolled in schools in Madhya Pradesh. This is only 32% of the total children with disabilities. Most of them (1.23 lakhs) were in elementary, with less than a thousand (769) children with disabilities enrolled at pre-primary level and 23,363 students enrolled at secondary level.

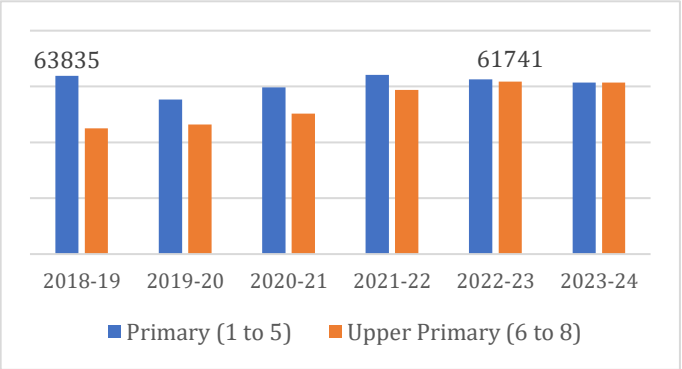

Figure 1: Break-up of children with special needs enrolled in primary and upper primary over the years in Madhya Pradesh (UDISE + multiple years)

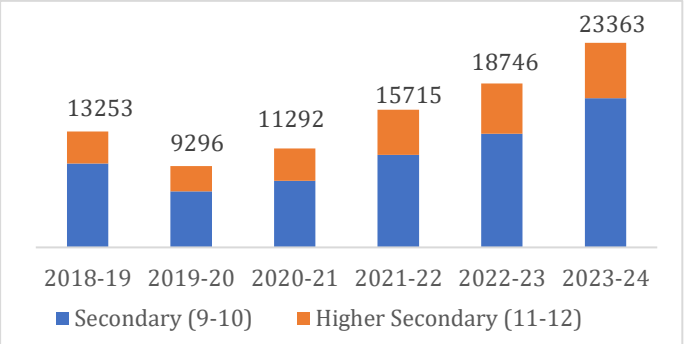

Figure 2: Enrolment of Children with Special Needs in Schools at secondary levels in Madhya Pradesh (UDISE + multiple years)

Drop out in elementary education has been reducing. Data from the state (figure 1) shows that once enrolled in schools, retention is being ensured at the elementary level. The enrolment in upper primary has increased and at par with that in primary since 2022-23. Considering the education period of 5 years, it is interesting to see that the number of children in three classes of upper primary (6 to 8 years) in 2022-23 is almost 96.71% that of children enrolled in five classes of primary school in 2018-19.

Transition to secondary school is still a major challenge. Global reports (UNICEF, 2021) also show that out-of-school rates increases during secondary school with 21% and 35% children one functional difficulty being out of lower and upper secondary schools as compared to 16% and 28% children without functional difficulties. A national

level study in India (Gupta, 2016) has also revealed that the education system is retaining only 12.02% children with special needs enrolled in class I to class XII. UDISE+ data also shows a significantly lower number of children with special needs enrolled in secondary and higher secondary schools (figure 2). The transition from upper primary to secondary at around 12.76% is still a challenge. Interestingly, the transition from secondary to higher secondary at around 82.77% is again good.

Learning outcomes of children with disabilities is also often lower than that of their peers without disabilities. Global studies (UNICEF, 2021) show that a much lower proportion of children with one or more functional difficulties, have foundational reading skills (21%) and numeracy skills (10%) compared to their peers without disability who reported higher proportions of 32% and 17% respectively.

There are multiple barriers in accessing healthcare and education facilities. There is often limited availability of secondary and tertiary health care and education services at local level. Then, there are challenges related to physical accessibility. According to members of the National Centre for Promotion of Employment for Disabled People (NCPEDP), less than 1% of the country's total number of educational institutions are disabled-friendly (Aggarwal, 2024). In Madhya Pradesh, for example, only 33.4% of schools had ramps with handrails (UDISE+, 2023-24). Similar situation was seen in the district hospital visited as part the study wherein the physiotherapy centre was on the second floor without any lift facilities. This makes it less usable for people with disabilities.

Rehabilitation services are most 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) is also available only at district headquarter. Furthermore, awareness related to the need and impact of therapeutic services among parents of children with disabilities is very low. There is a tendency to expect quick results and nor continue with the required number of therapeutic sessions. Even otherwise it was found that parents focus more on treatment than therapeutic services, a practice that is unfortunately encouraged even by medical practitioners.

Attitudes of service providers coupled with lack of training limits approachability. Apathy of medical practitioners, in particular, was highlighted as a major challenge by multiple key informants during interviews. Private schools are often reluctant to provide admissions to children with disabilities. Then there is lack of training among frontline health and education workers. In Madhya Pradesh, almost 96% of school teachers are not trained to deal with the special needs of these children (UDISE+, 2021-22). The vast frontline health care work force of ASHAs, Anganwadi workers, and Special Newborn Care Unit (SNCU) staff specifically working for children is potentially a great opportunity for reaching out to children with disabilities, provided their capacities are adequately enhanced.

Children with disabilities also face additional impediments to basic water, sanitation and hygiene (WASH) services, which hampers access to education. Inadequacy of water and sanitation services further adds to the challenges to accessing basic needs. In the state, for example, only 21% schools have disabled friendly toilets (UDISE+, 2023-24). Access to menstrual hygiene is an even greater challenge, especially for girls with disabilities.

Indifference and unawareness among parents of children with disabilities adds to their woes. Many parents are content with cash transfers and not really worried about health care and rehabilitation services for their children, leading to their needs being neglected. A stimulating home environments and nurturing relationships is often lacking. 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.

Intersectionalities related to sex and residence further increases the vulnerability. Girls with disabilities are often discriminated in terms of enrolment in schools and referral services. Children with disabilities living in child care institutions (CCIs) and orphanages are often overlooked for their nutrition or rehabilitation needs due to inadequate staffing and discriminatory practices. Children with disabilities, especially girls, are also more vulnerable to sexual violence.

PART 3 GOVERNANCE FRAMEWORK FOR CHILDREN WITH DISABILITIES

There are a number of legislations protecting children with disabilities against discrimination and mandating for their equitable access to resources, opportunities and voice. The Right to Education (RTE) Act, 2005, includes specific provisions for children with disability to pursue free and compulsory elementary education. The Rights of Persons with Disabilities Act (RPDA), 2016 mandates the government to take measures to ensure that children with disabilities enjoy their rights equally with others. The new Mental Healthcare Act (MHCA), 2017, purports a more patient centric and rights based, with specific provisions to safeguard the interests of children with disabilities.

These legal mandates have been supplemented by various policies to realise the rights of children with disabilities. The National Health Policy (2002), for example, includes early detection and response to early childhood development delays and disability, adolescent and sexual health education. The National Early Childhood Care and Education (ECCE) Policy (2013) recognizes the importance of investing in early childhood development, with focus on children at risk of developmental delays and disabilities. The National Policy of Persons with Disabilities (2006) endorses the right to development with dignity and equality for children with disabilities along with focus on educational rehabilitation including vocational education. The National Education Policy (2020) includes recommendations for non-discrimination in schools, accessible infrastructure, reasonable accommodations, individualized supports, use of Braille and Indian Sign language in teaching, and monitoring among others. The policy also includes provisions for special schools as an option for children with benchmark disabilities, and for recruitment of special educators with cross-disability training and incorporates disability awareness within teacher education.

The Government of India (GoI) has also introduced many programmes and schemes specifically targeting children with disabilities. The Rashtriya Bal Swasthya Karyakram (RBSK) under National Health Mission (NHM specifically focuses on screening of all children to enable early detection (including for developmental delays), free treatment and management, including surgeries at tertiary level. There are various national programmes addressing the specific needs of people with disabilities including the National Programme for Control of Blindness and Visual Impairment (NPCBVI)- which has a target for distribution of free spectacles to school children; National Programme for Prevention and Control of Deafness (NPPCD); the National Mental Health Programme (NMHP); and the recently launched Sickle Cell Anaemia Elimination Mission.

There is a scheme for Assistance to disabled persons for purchasing / fitting of aids / appliances (ADIP). The scheme has specific provisions for children with disabilities including a separate ADIP SSA (Samagra Shiksha Abhiyan) component which has provisions for including children with less than 40% disability, and an adapted minimum time of assistance is one year for customized items like fitments of orthosis / prosthesis, learning material etc. The scheme also specifically provides for cochlear implant and post operative therapy and rehabilitation for children with hearing impairment.

The Department for Empowerment of Persons with Disability (DoEPwD), GoI, also supports voluntary organizations for services related to rehabilitation of people with disabilities, including early intervention, development of daily living skills, education and training through the Deendayal Disabled Rehabilitation Scheme (DDRS). 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.

To promote access to education, special schools and hostels for children with disabilities, are run by various state departments either directly or as a government-aided institution. Additionally, scholarships are provided both by the national and state government for children with disabilities right from primary school to higher education levels.

Additionally, there are general programmes and schemes with potential to benefit children with disabilities. These programmes aim to achieve universal access and coverage, which means

children with disabilities are equally entitled to the benefits. The NHM) under the child health programme includes interventions for newborn health; nutrition; pneumonia and diarrhoea; birth defects, developmental delays and deficiencies; and immunization. The Ministry of Health and Family Welfare (GoI) has also specifically issued "Accessibility Standards for Health Care" in 2023 in compliance to the implementation of the RPDA (2016).

The Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (AB PM-JAY) provides health cover of Rs. 5 lakh per family per year for secondary and tertiary care hospitalization- including to all people with disabilities who are eligible, with special medical and surgical packages covering their needs. Although, given the limitation of eligibility, there are demands seeking inclusion of people with disabilities without any income as well as age criteria. In 2023, the Insurance Regulatory and Development Authority of India (IRDAI), vide a circular, has mandated insurers to offer products that provide health insurance coverage to persons suffering from disabilities.

The Poshan Abhiyaan aims to reduce stunting by improving the utilization and quality of key anganwadi services. There are specific provisions for growth monitoring, hot meals and Take-Home-Ration (THR) under the scheme. Universal access to ECCE is also envisaged mainly through the government run anganwadi centres, although the Samagra Shiksha Abhiyan (SSA) also supports setting up of ECCE/pre-school centres, attached to primary schools.

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. It is expected that through the Divyang protocol, district administration will be guided in addressing special needs for education and nutrition, and providing Swavlamban Cards for the empowerment of children with disabilities and their families. The Ministry has also proposed that the developmental milestones of the children will be tracked on the Poshan tracker and the data will further support convergence between relevant ministries.

The Department of School Education and Literacy, has specific components to promote inclusive education under the Samagra Siksha Abhiyan (SSA). This includes, among others a recurring grant of Rs 3500 per year per child with disability for aids and appliances, teaching material, etc and provision of stipend of Rs 200 per month for 10 months for girls with disabilities.

The Swachh Bharat Mission (SBM) launched in 2014, has a strong thrust on equity, and gives attention to the special needs of people with disabilities especially in rural areas. The Government of Madhya Pradesh (GoMP) also has a specific "Udita" scheme to address menstrual hygiene needs of adolescent girls. Unfortunately, there are no specific targets for girls with disability included yet in the scheme.

PART 4 IMPLEMENTATION STATUS

Early detection and treatment, although increasing under RBSK is still a challenge. In the last decade (2013-24) around 996.78 lakh children have been 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

The department reports a high screening rate of 83.80%, however, as per 2020 population projections for Madhya Pradesh, the actual 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 to enable reaching out to children with disabilities. Lower screening is reflected in low identification of children with developmental delay- 3.9% as against the department's norm of 10%. With only 0.74 lakh cases of development delays identified in 2023-24, this points to a gap of 1.16 lakh missing count of children with disabilities. Although the RPDA (2016) mandates screening all the children needs to be undertaken at least once in a year for the purpose of identifying "at-risk" cases, this still not happening in a targeted manner. There is the need to have a focused screening campaign for children with disabilities.

Unfortunately, data on the referrals and treatment support provided to children with disabilities is not available with the Department of Health and Family Welfare (GoMP). However, as per the framework for implementation of 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. And although the targets have increased in recent years to 93,000 in 2024-25 and 97,000 in 2025-26; the actual implementation status needs to be monitored.

Access to anganwadi centres and nutrition programmes is cultivating. The Anganwadi worker is generally well aware (and often sensitive) to the needs of children with disabilities in the neighbourhood, although she might have not received any formal training. Children with disabilities are not kept full time at the anganwadi centre, but are provided with services such as growth monitoring (weighing) and take-home ration (THR). The coverage of children with disabilities under the programme is, however, completely untracked, making it difficult to analyse the actual coverage. There are also no specific toys or learning devices available at anganwadi centre. Running in small areas, it is difficult for these centres to retain and care for children with disabilities. This further limit the access to EECE for children with disabilities, as the programme is mainly being targeted through anganwadi centres.

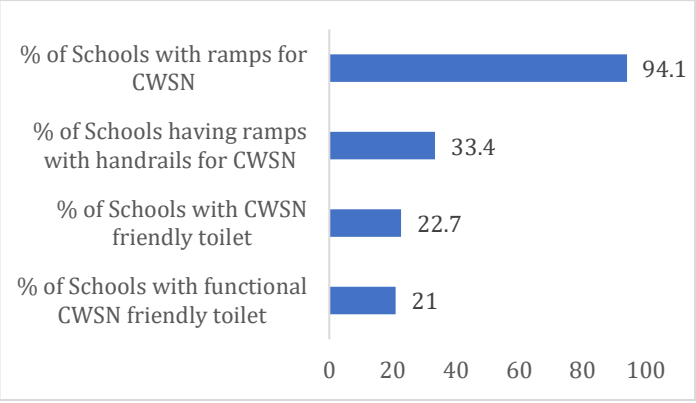

Figure 3:Accessibility of elementary school infrastructure in Madhya Pradesh (UDISE + 2023-24)

Limited early intervention projects are being supported through Deendayal Disabled Rehabilitation Scheme (DDRS). There are currently 12 DDRS projects being supported in Madhya Pradesh (DoEPwD, 2023-24). All the projects are targeted for children with disabilities, however the number of beneficiaries in the last few years has not only been stagnant but also less than a thousand (figure 4), which is very less compared to the requirement.

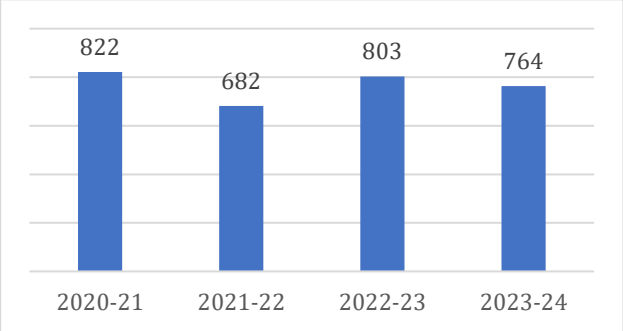

Figure 4: Number of beneficiaries under DDRS in Madhya Pradesh in last four years
Source: DoEPwD Annual Report (2023-24)

Accessibility to schools is improving but constraints exist. The SSA has also made specific provisions for children with special needs. Unfortunately, data on number of special educators, provision of teaching learning material (TLMs), stipend, home-based schooling, learning levels, etc. is not available. Key informant interviews, however, reported that while braille textbooks are being distributed in schools, the children don't know braille and hence cannot use the same. Further, recent reports from the state (UDISE+, 2023-24) show that only 21% of elementary schools have functional disabled friendly toilets, and only 33.4% had handrails along with ramps (figure 3).

What is even more critical is that government schools supported by the state government are most lagging behind especially in terms of disabled friendly toilets. UDISE+ data (2023-24) also shows that only 13% of the state government schools has such toilets. Even more disturbing is the fact that only 21,633 (4%) of the total six lakh teachers have been trained to address the needs of children with disabilities.

Mainstreaming of students is still lagging behind and special schools are limited. Getting admissions in mainstream schools remains the biggest challenge. It was highlighted multiple times by all stakeholders- parents and civil society groups that even though it was mandatory for schools to accept children with disabilities into the system, schools especially non-government schools were highly reluctant to provide admissions.

Added to this is the fact that there are fewer special schools for children with disabilities, especially at higher levels. As per UDISE + 2021-22, there are 346 special schools in the state of Madhya Pradesh. Around 80% (277) of these cater to students at primary or upper primary level. Almost half of these are run privately, or are government-aided institutions, which mostly do not cater to the needs of children with intellectual disabilities.

Here again, data discrepancies were observed. While UDISE+2021-22, mentions only 15 institutions run by SJED, data received from the department shows that there are 53 schools visually, hearing and speech impaired students run directly or aided by the department. Further a review of the available enrolment data (table 2) of SJED supported institutions shows only 3863 students which is a very miniscule number compared to the total number of children with disabilities in the state. Data also shows that a high 60% of the children enrolled are residential, further pointing to the need for more residential facilities for children with disabilities. This is especially required for girls with disabilities, who constitute only 29% of the total enrolment. Interestingly, while overall the enrolment is higher as residential students (60%) for girls it is lower at only 43.9%. There is thus the need to have more dedicated residential facilities for girls with disabilities.

Table 2: Students with disabilities in Special Schools Run/Aided by SJED in Madhya Pradesh, 2023-24

Type of School Management	Boys	Girls	Total
Government Run (Residential)	641	57	**698**
Government Run (Non-Residential)	425	210	**635**
Government Run (Total)	**1066**	**267**	**1333**
Government Aided (Residential)	1061	582	**1643**
Government Aided (Non-Residential)	595	292	**887**
Government Aided (Total)	**1656**	**874**	**2530**
Total	**2722**	**1141**	**3863**

Source: Social Justice and Empowerment Department (SJED)GoMP

Another important aspect is the need for more funding. Data shows that while one-third of special schools are run by the department of education, the allocations for the same, under the budget head 7734, although increasing in the last few years, is still very limited (figure 5). There are also limitations related to fund allocations by SJED for special schools. Further there are challenges in utilization of the allocated budget by the education department, although, the utilization rates are good for SJED schemes at around 94% (for 0073) and better at 73% (for 0079).

The quality of the special schools seems decent with basic infrastructure facilities. Field visits to residential facilities of education department, highlighted that while scope of improvement exists, the situation on the ground is better. The place was reasonably clean and had information posters everywhere. The hostel had a well-equipped seminar hall, kitchen, dining cum play area and dormitories for students. There were some tools and equipments available for the children in the seminar hall. Although, neither the hostel (reportedly the attached school) has any accessibility features. Even tactile flooring was

missing. In fact, the dormitory of the visually impaired had a step down just from the room.

The quality of the institutions currently being run especially by SJED, was found to be adequate during the field visit. Basic infrastructure facilities were available, the interior was well maintained, and had accessibility features like ramps, railings and tactile flooring in place. Although there are some gaps and considering that it's a residential school, there needs to be some more work on the outside both in terms of visual appeal and security. Currently, there is no security guard or CCTVs observed.

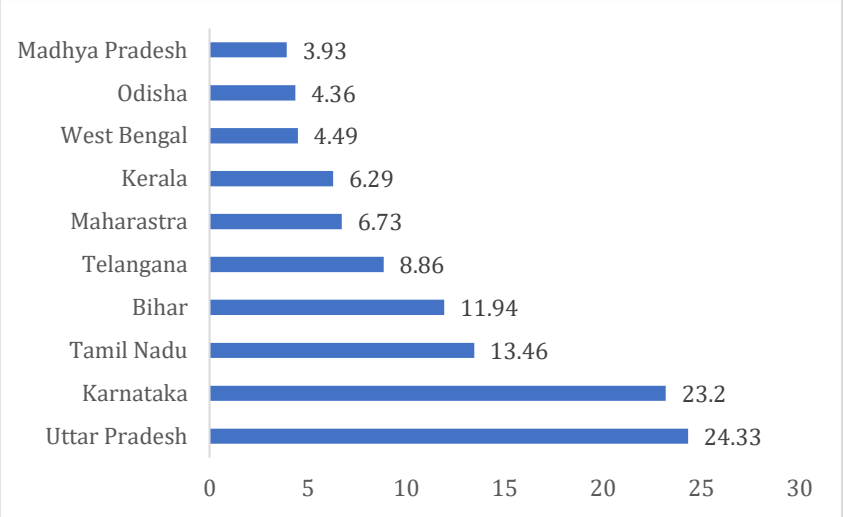

Figure 5: Budget Allocations (in crore rupees) in the last four years for special schools in Madhya Pradesh
Source: Child Budget Statement GoMP (multiple years)

It was also seen that against the 100 seats available in the institution, there were 193 students. In fact, in the previous year there were 239 pass outs. There also seems to be a gender bias with lesser number of girls enrolled, probably as there are no residential facilities for girls. The further points to the demand for such institutes and the need for the GoMP to increase the number of residential special schools, especially for girls.

Availability of trained teachers is a major gap area faced by the special schools. This issue was raised consistently in all key informant interviews, and is supported by UDISE plus data which shows only 4% of teachers being trained. The type of teacher training programmes conducted are also limited. Teacher's training is undertaken at CRC but it is mainly related to curriculum up dation. There are no special educator's trainings.

In the education department run hostel visited, there was only a full-time warden and special educator for hearing impaired, apart from support staff, were available. For visually impaired students services of a part time special educator (from Aarambh- a local NGO) was being availed. In the SJED run residential school availability of teachers was seen as a major concern area with especially limited access to students for STEM and vocational education. Currently for a pre-primary (kg 1) to higher secondary (XII) school, the school had only 5 teachers for visually impaired and 3 teachers for hearing impaired. This resulted in multiple classes being run parallelly (around 5 classes per period). There was a very good drawing teacher but no music teacher. Similarly, there was a computer lab but no computer teacher.

Scholarships available for children with disabilities is highly underutilized. The DoEPwD (GoI) implements six scholarship schemes for students with benchmark disabilities; however, Madhya Pradesh has also not been able to realize the full potential of scholarship slots in many years. This results in the state getting much lesser allocation compared to other states (figure 6). A review of data of last 10 years shows that although, the state has made significant improvements in select years like 2015-16, 2020-21, and 2021-22;

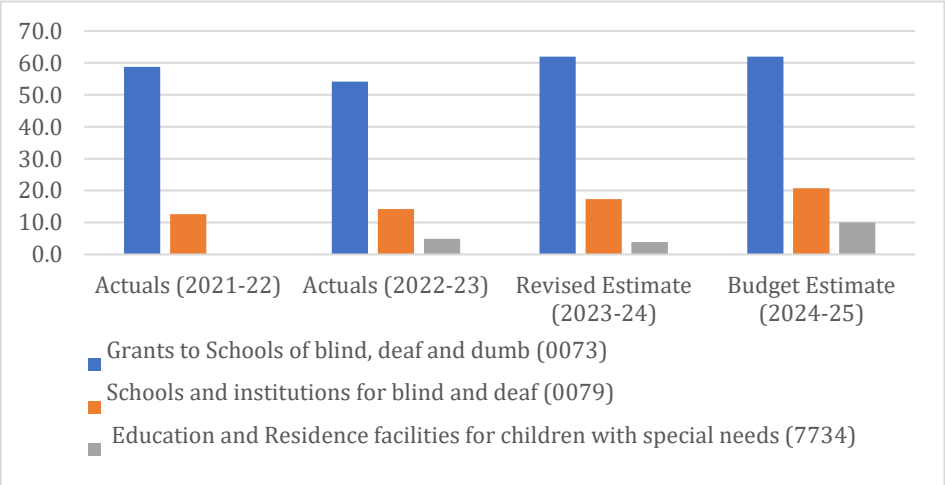

Figure 6: State-wise fund released under various National Scholarship Schemes in 2023-24

but in the rest a year-on-year decline in the number of beneficiaries is seen. This is a major area of concern as the average number of annual beneficiaries of 4,355 is a very low number, covering only 5.23% of the total 83,258 children aged 6 to 15 years having UDID cards. Equally discerning is the average amount of scholarship per student which comes to around INR 19,000 in the last five years. This further points to the fact that scholarships are probably being availed mostly at pre-matric level and not at higher levels. The state does provide a significant high number of beneficiaries scholarship under its own scheme (figure 7).

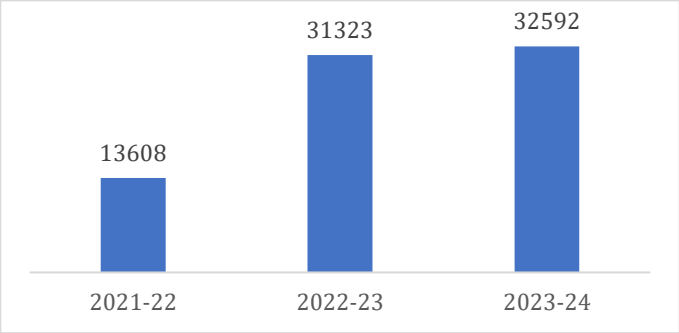

Figure 7: Beneficiaries under State Scholarship Scheme for Children with Disabilities in the last three years in Madhya Pradesh

However, in terms of amount of scholarships being received the average seems to be declining as the actual expenditure is stagnant. Additionally, the state also provides support for higher education under the "Madhya Pradesh Higher Education Fees, Disability Living Allowance, Transport Allowance Scheme for Disabled Students" scheme. However, the figures in the last three years have been dismal at 13, 7 and 12 for 2021-22, 2022-23 and 2023-24 respectively.

Access to assistive devices for children is still not as required. The overall coverage under ADIP is high but coverage under ADIP SSA is less. Calculation using multiple target estimations shows the coverage to be 37% at best and 11% at least. It is important for the state to focus on coverage of children with disabilities for provision of assistive devices. Equally important is to ensure maintenance of proper data to ensure monitoring. Currently, it being a central sector scheme, substantial data discrepancies are being observed.

Another key gap is the time delay between assessment and provision of the device to the child, which often results in the assistive device, when actually provided not remaining relevant for the growing child. 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 CCIs, there currently seems to be no coverage of children with disabilities in CCI as part of the scheme. Another key gap is the very limited number of cochlear implants and post operative therapy and rehabilitation for children with hearing impairment being supported in the state. 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 8).

GoMP also provides students with disabilities additional benefits like provision of laptop and motorised tricycle under the Chief Minister Diyang Siksha Protsahan Scheme. In 2023-24, around 537 students got laptops and 604 students received motorised tricycle under the scheme.

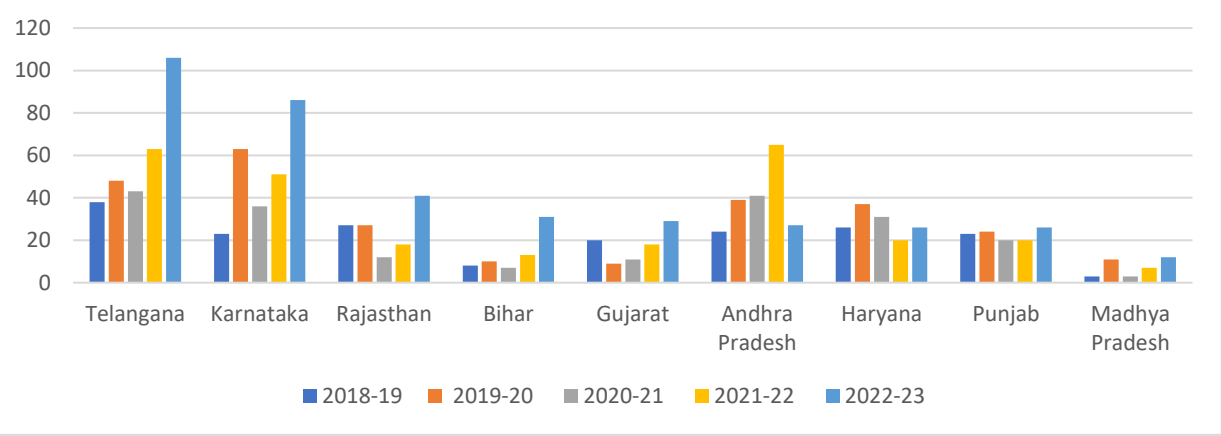

Figure 8: Cochlear implant surgeries conducted in various states in last five years
Source: LSUQ 3003, 2023

Access to therapeutic services through DDRCs and DDRS is also not adequate. The government run DDRC, are only available at district headquarter, with nil to limited off-campus outreach. 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. Parents of children with disabilities, and even frontline workers at anganwadi are not fully aware of the services and its importance. Also, the infrastructure, services and equipments available with respect to the specific needs of children with disability is inadequate.

Field visit to a DDRC revealed that in some districts the state has allocated a separate building with open lands. Basic infrastructure including staff rooms, therapy rooms and accessible toilets are available. Other accessibility features in the DDRC, however, needs to be improved. Furthermore, access to tools for teaching and learning, need to be focused on. For example, in the DDRC visited 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. Some of the rooms in the DDRC were simply being used as storage for ALIMCO provided devices. These could be converted into more usable rooms like library, audio-visual or playroom. Training of staff is also an issue. 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. Training on new technologies like using telescope, daisy player, braille watch, etc. is especially required. Annual trainings for staff should be considered.

Making DDRCs more user friendly and service intensive will also increase the number of users (beneficiaries). Currently, the number of users seems less. Unfortunately, data on beneficiaries, although maintained at the DDRC is not collated at higher levels to enable any analysis.

It is critical to invest more to increase the quality of DDRC services. However, of the DDRCs set up in in all districts of the state, in 2023-24, the central has provided Grant in Aid (GIA) to only 27 DDRCs (DoEPwD, 2023-24). 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).

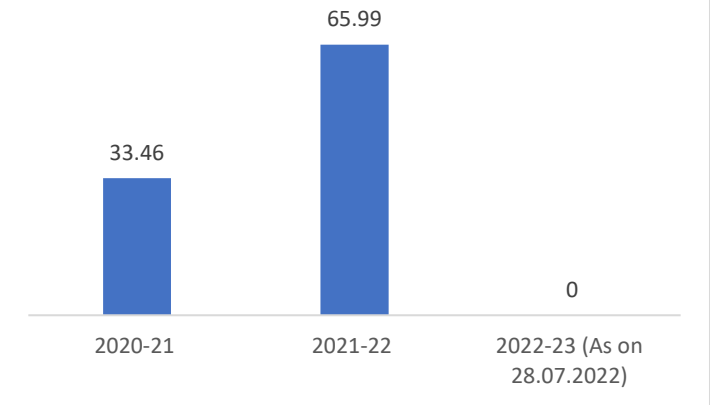

Figure 9: Grants-in-Aid released to DDRCs in Madhya Pradesh during the previous years (amount in lakh rupees)
Source: RSUQ No. 2056 (2022)

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. Furthermore, there are no proposals under community-based rehabilitation (CBR) projects as part of DDRS from the state.

Most critical is the data limitations both in terms of status of outcome as well as coverage of children with disabilities under major schemes. Tracking of coverage children with disabilities under government schemes is significantly lagging. This inhibits monitoring of coverage and evidence-based planning. Further, there is complete lack of data on outcomes related to children with disabilities. UDISE plus is the only data source that collects and publishes data related to children with disabilities. None of the other reliable sources for child data like the national family health survey (NFHS), the Sample Registration System (SRS), and the National Achievement Survey (NAS), provides information on status of children with disabilities, separately. Availability of small-scale research studies at the state level on concerns of children with disabilities and access to government programmes is also limited.

PART 5 RECOMMENDATIONS

INTERDEPARTMENTAL MECHANISMS

An inter departmental committee for providing inputs to improve status of children with disabilities in the state can be formed with SJED, WCD, Health, and Education departments on board. In this regard, the existing current advisory board of SJED can be extended with representation from the above departments and up dation of the terms of reference to focus on children.

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. The state can also consider putting a budgetary target of 4% allocation for children with disabilities as part of the child budgeting process.

Tracking of data on children with disabilities covered should be initiated on a priority basis. A state-level portal integrated with Samagra platform can be created for all data related to coverage of children with disabilities under various government schemes. The Samagra platform can also be co-opted to monitor the status of children with disabilities who pass class VIII and are enrolled in class IX.

The state should publish a bi-annual report on the status of children with disabilities, the various programmes and schemes targeting children with disabilities, and their coverage under the various initiatives.

Research studies using primary data collection needs to be supported to understand the status of health, nutrition and education of children with disabilities in the state.

SOCIAL JUSTICE AND EMPOWERMENT DEPARTMENT (SJED)

The SJED needs to set up a separate division for children with disabilities to implement and monitor the coverage of under its various schemes. The division should also facilitate and review the status of implementation of central sector schemes such as DDRS, DDRC, etc

Primary survey needs to be conducted to get better estimates to children with disabilities. The state can consider using the "Child Functioning Module" developed by UNICEF and Washington group for a more standard approach for identification.

Tracking of data on children with disabilities covered should be initiated on a priority basis for ADIP SSA, DDRS and DDRCs. Small research studies on status of services provided by the government (e.g. DDRS and DDRCs) in select districts need to be supported at regular levels.

Access to assistive devices through ADIP SSA needs to be improved. 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. The scheme needs stronger monitoring. Also consider having a common database of all beneficiaries covered under ADIP SSA in the state. Also consider separately tracking details of funds utilized for ADIP SSA and under ADIP (including CSR) specifically for children with disabilities.

There is an urgent need to focus on cochlear implant and post operative therapy and rehabilitation for children with hearing impairment. SJED needs to conduct awareness campaigns and drive for increased coverage of beneficiaries, especially given that the state has a high proportion of children with hearing impairment

Awareness camps on need for therapies and services provided by the DDRCs should be conducted in all districts. Funding for DDRCs need to be increased. SJED needs to support development of proposals for DDRCs in line with scheme guidelines and ensure that central funds are received by all DDRCs in a timely manner. SJED should also 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. 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.

Support local NGO to increase the number of DDRS in the state. There should be at least two centres per district with higher numbers in larger districts. Additionally explore DDRS projects for 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.

Allocations are also required by SJED for setting up special schools at secondary and higher secondary levels. There is a specific need to focus dedicated residential facilities for girls with disabilities. Allocate dedicate funds for setting up hostel facilities for girls with disabilities, or ensuring that the existing girls' hostels in each block has a dedicated wing for girls with disabilities retrofitted to suit their needs and made accessible.

The state should focus on realizing the full potential of scholarship slots provided by national government. Awareness campaign cum scholarship registration camps needs be organized in the beginning of each academic session to ensure enrolment of all such children in secondary schools and under the pre-matric scholarship program of the national or state government.

- Increased monitoring of the enrolment and renewal of students availing national and state scholarships needs to be undertaken.
- The SJED should set a target of achieving 100% coverage of the allocated slots for national scholarships to the state for the next five years.

While the national scholarships provide 50% reservation for girls, the state could provide an **additional incentive for girls with disabilities**. This incentive can be provided to the parents or directly to the schools to encourage them to enrol girls with disabilities.

Organize programmes to educate parents about the right to education can encourage them to advocate on behalf of their children. At the community level, stigma and discrimination need to be addressed and awareness of the multiple benefits of inclusive education increased. Gram Panchayats should be actively involved in the process.

Quality of teachers with teaching aids need enhancement. Along with training to teachers, consider suggestions for B. ED with special ability course in special schools run by SJED. Explore the potential of special B.Ed. admission free coaching programme for residential school students in XI and XII standards to enable them to get admission in B.Ed. and train as teachers and special educators. Based on a preliminary assessment in select districts, a coaching programme for admission in B.Ed. courses can be run within residential school students in XI and XII standards.

Explore the potential of a volunteer programme for “Persons with Disabilities”. This can be undertaken by approaching old age-homes, Science Colleges, Private Schools, for volunteers to teach STEM courses in CWSN schools. A limited period (6 to 10 days) special educator programme can be curated and conducted for Masters students in science colleges and/or retired professors (educators) and they can be recognised by the Department to be enrolled as guest faculty in residential schools or government schools to teach CWSN.

CSR foundations can also be approached for corporate volunteers for personality grooming, English speaking and career mentoring in CWSN schools. An orientation programme for the a select group of volunteers can be conducted with support from local NGOs like Arushi. They can then be enrolled at different residential schools and child care institutions for CWSNs. This will not only provide support to children but also create a very high level of sensitization and understanding in the corporate world on inclusion of persons with disabilities.

SJED should consider commissioning an accessibility audit for institutions related to children. In first phase all District Hospitals, Primary Schools and DDRCs can be covered and in the second phase Anganwadi centres, Secondary Schools and Primary Health Centres (AAMs) can be covered. 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 needs to be undertaken. Partner with select national institutes for conducting an advanced (5 days) training for different specialist at the DDRCs. 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.

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.

DEPARTMENT OF WOMEN AND CHILD DEVELOPMENT DEPARTMENT (WCD)

Tracking of children with disabilities using POSHAN tracker and health cards for nutrition coverage and immunization services specifically needs to be undertaken. Tracking of data on children with disabilities covered should be initiated on a priority basis for Ladli Laksmi and project Udita; and Beneficiaries having children with disabilities under Ladli Behna scheme.

Undertake special drives for providing Swavlamban Cards for the empowerment of children with disabilities and their families under Poshan Abhiyan. Training of all Anganwadi workers on MWCD's protocol on "Anganwadi Protocol for Divyang Children" needs to be undertaken.

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.

Anganwadi centres, including those in urban areas need to be audited for accessibility and retrofitting of all anganwadi centres. Where the number of such children enrolled in a centre is high (5 or more), there needs to be an additional dedicated helper in place, who is trained on the addressing the specific needs of children with disabilities.

A kit for children with disabilities aged 24 to 59 months can be designed, developed and provided at the anganwadi centre. WCD and SJED can coordinate for DDRC professionals to organize camps at anganwadi centres for distribution of these kits and training on parents of children with disabilities to provide early stimulation and responsive care. Activities can include reading books or looking at picture books with the child; telling stories; singing songs to or with the child; taking the child outside the home; playing with the child; naming, counting or drawing things for or with the child. The kit can include playthings such as toys, reading and picture books, stories for parents, etc.

Anganwadi services especially **THR provision can be extended to children with disabilities between 6 to 18 years,** who are not attending any educational institution.

Have a targeted programme for children with disabilities in Child Care Institutions (CCIs). Mandate provision of fortified food material to CCIs on lines of Poshan Aahar and PM Poshan schemes. Organize camps for vitamin A supplementation, iron supplementation and deworming medicine for worms' infestation, under NHM for children with disabilities in CCIs. 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.

Specific camps also 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. Counselling programmes should be conducted at regular intervals to support children with intellectual disabilities living in CCIs.

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.

Organize specific trainings of Anganwadi workers for supporting adolescent girls with disabilities on menstrual hygiene and use of sanitary products as part of project Udita.

DEPARTMENT OF HEALTH AND FAMILY WELFARE (DHFW)

As mandated by the Rights of Persons with Disabilities Act (RPDA, 2017) **screening all the children needs to be undertaken at least once in a year** for the purpose of identifying "at-risk" cases. This should be undertaken in mission mode by the DHFW in collaboration with SJED.

The child screening rate under RBSK needs to be optimized 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. 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. Also need to focus on increased screening and treatment referrals for girls with disabilities under RBSK. Special screening camps for girls with disabilities can be organized with support from gram panchayats. Set targets for girls with disabilities being covered under various national programmes for treatment at secondary and tertiary levels.

Specific (updated) data on the treatment support provided to children with disabilities should be tracked and made available in public domain. Increase focus on providing free spectacles to school children suffering from refractive errors. Higher targets to be set with focus on achievement under National Programme for Control of Blindness and Visual Impairment (NPCBVI) for free spectacle distribution. Also need to increase monitoring of actual coverage.

Publish a primer on the status of children with disabilities in the state based on the national family health survey (NFHS). Undertake a specific 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.

Tracking of data on children with disabilities covered should be initiated on a priority basis for various national programmes related to blindness control and visual impairment, hearing impairments and mental health; Ayushman Bharat programme, along with status of insurance claims. Strengthen implementation of PM-ABHIM to ensure sex, age and disability disaggregation (SADD) in health data.

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.

Strengthen implementation of the Mental Health Act. Mental health review boards (MHRB) need to be operationalized across the state. 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

Organize workshops and seminars on issues of children with disabilities for medical professionals at state and district level. Organize specific trainings of ASHA workers on identification of children with disabilities and motivation for linking with therapeutic services. Also train them on supporting adolescent girls with disabilities on menstrual hygiene and use of sanitary products.

SCHOOL EDUCATION DEPARTMENT

Most important is to ensure enrolment of children with disabilities in mainstream schools. An advisory/government order (GO) can be issued in this regard from the District Education Officer to all private and government schools stating disciplinary action against schools which refuse admissions to children with disabilities. A helpline number (dedicated or in coordination with existing ChildLine

number) needs to be initiated to take complaints and support enrolment of children in schools.

Special enrolment drives can be undertaken in in coordination with the local bodies for children with disabilities in primary schools. This can also be promoted as a low-cost activity within the Gram Panchayat Development Plans (GPDP).

Support for special education from private, sector needs to be explored. Seminars may be organized for CSR funding to be provided to schools on enrolment of children with disabilities to compensate for the additional resources required for his or her education. Such transfers can also be provided directly to private schools to encourage them to enrol children with disabilities.

Strengthen accessible infrastructure in schools. Develop a standard operating procedure (SOP) to benchmark schools with disability friendly indicators. Conduct a state-wide accessibility audit of all government and government-aided primary and secondary schools. Based on the retrofitting needs emerging from the above, increase allocations under SSA for making schools more accessible. Education department should target 100% coverage of all government and government aided schools to have ramps with handrails and disabled friendly toilets in the next three years. The disabled friendly toilets in secondary schools also need to include provisions menstrual hygiene management. Funds need to be allocated for the same as part of SSA and implementation of the same to be actively monitored.

Increase access to ICT by creation of computer labs with accessible systems in all schools. In addition to laptops, tablets can also be considered to be provided to children with disabilities.

Consider allocating 2% of SSA budget for inclusive education. Allocations for Education and Residence facilities for children with special needs also needs to be increased.

Improving learning outcomes is equally important. There is an urgent need for training of all teachers linked with education department on awareness related to disability issues and potential of children.

Annual trainings and refresher courses from one to six days need to be organized. There should be a training calendar plan in summer vacations for 10 days for visually impaired and 6 days for hearing impaired, initially with not more than 25 teachers per training, followed by refresher trainings every 2 to 3 years. The trainings can also be conducted at district level. STEM teachers need to be trained to teach students especially those with visual impairment (a batch of 50 teachers can be developed in each district). Focus on big size model schools like CM Rise and PM Shri schools to include and track the progress on children with disabilities. These schools should have adequately trained teachers, equipment, infrastructure etc. as one of their priorities.

A special educator programme for teachers can be piloted in one district based on the following points

- Identify 25 teachers for at least seven subjects (English, Hindi, maths, social science, science, physics, chemistry, biology, commerce, accounting, etc.) in the district for the training (below 45 years of age)
- Conduct dedicated training programmes (6 days for hearing impaired and 10 days for visually impaired) in the district
- Identify 50 teachers (from the above group) in the district and facilitate a 45 days special educator programme for them.
- Conduct an impact assessment of the programme after 2 years to identify measures for scaling up.

Conduct monthly **sign language training courses** for teachers in partnership with District Institutes of Education and Training (DIET) and Indian Sign Language Research & Training Centre (ISLRTC), New Delhi.

Conduct half yearly **braille training courses** in partnership with DIET and National Institute for the Empowerment of Persons with Visual Disabilities (NIEPVD), Dehradun.

Coordinate with the National Achievement Survey (NAS) to **publish data on learning outcomes for children with disabilities** separately as part of the state report cards.

This policy brief has been developed by Dharmistha Chauhan, Consultant UNICEF. The brief is based on two working papers for Children with disabilities in Madhya Pradesh "*Access to Health, Nutrition and Therapeutic Services*" and "*Early Childhood Learning and Access to Education*" supported by UNICEF Bhopal Office. The report findings were submitted to sections in UNICEF and presented to Social Justice and Empowerment Department (SJED), GoMP. Comments received have been incorporated accordingly. **For more information, contact:** Pooja Singh, Programme Specialist, posingh@unicef.org